



SPECIAL EDITION

FEDS News Today

Volume 25 - Issue 5

May, 2013

Our Mission

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.

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

Inside this issue::

Focus on Family	2
Rising Star Academy	3
Summer OT Group	4
Love & Logic	5
Sibling Tips	6
Upcoming Events	8

A GREAT BIG “THANK YOU” TO LUCY TALBOT!!

The time has come for Lucy to retire from her Board position with FEDS. We offer our sincere thanks and appreciation to a friend, colleague, and leader.

Lucy has been an integral part of FEDS for more than 20 years. Under her leadership, our group has grown and prospered. She is an advocate for ALL people with Down syndrome, showing the world their capabilities and accomplishments. When parents need support and encouragement, Lucy is always there with an open ear and kind words.

There are many programs and activities that Lucy has been instrumental in starting. Under her guidance, we were able to put on five Fashion Shows, where our children were the “stars”. She worked to get FEDS recognized as an “independent” so our young athletes could participate in Special Olympics. With the help of NDSS materials, Lucy and her friends started the very first “Changing Lives” program in Michigan. Many, many other activities would not have happened if Lucy hadn’t said “let’s try this” and led us all with her determination and encouragement.

Families Exploring Down Syndrome and ALL its members owe Lucy Talbot our thanks and gratitude for helping make our group the success it is today. We look forward to seeing you at our future functions, just enjoying yourself and not having to do any work!

WE WISH YOU ALL THE BEST!

About this Special Edition...

As you might guess from the above article, these are challenging times for FEDS leadership. Your FEDS board asks for your patience while we reorganize ourselves, reallocate assignments, and refocus our efforts on behalf of our members. We hope the resulting FEDS is a group in which you will continue to be proud to be a member.

While we are not yet prepared to do a full newsletter, we thought it was important to let you know about the leadership changes, and also about items that were omitted from the previous newsletter, such as summer scholarship information.

We Have A New Email Address and Facebook Page!

Our email address has changed to FEDSofmichigan@gmail.com. Please take note of it and add to your contacts. Thank you!

Our Facebook name has also been changed to **Families Exploring Down Syndrome of Michigan**.



You can also follow us on Twitter at <https://twitter.com/FEDSMichigan/>



Focus on the Boyer Family

"They are both boys and they think one has Down syndrome", I managed to say to my sister while crying uncontrollably. What was supposed to be a joyful ultrasound, unveiling the gender of our twins, turned into one of the scariest days of our lives. Scary because we were entering a world that was unknown to us.

We thought we were just given the hardest news we would ever hear, but at 24 weeks our priority changed from focusing on Down syndrome to fighting for the boys' lives. Casey developed hydrops, which is the accumulation of fluid in tissues or cavities in the body. Heart failure is common with hydrops because the heart has to work overtime. The doctors were also extremely concerned with our twin Blake, as he could go into distress due to his brother's hydrops. Not one doctor or specialist was hopeful that Casey would survive. It was our family and friends who continuously held on to hope and prayers. Every day, I continued hearing strong heartbeats as they monitored my babies in the hospital. Every day, we prayed for a miracle. And that miracle, we did receive! At 28 weeks



the hydrops started to dissipate and was completely clear within a week. I was sent home on bed rest and delivered my amazingly strong boys, Blake and Casey, at 38 weeks!

And there we were...a happy family. A crazy, sleep-deprived, can't-see-straight, non-showered, family of newborn twins, but yes indeed we were happy. And oh yeah, Casey just happened to have Down syndrome.

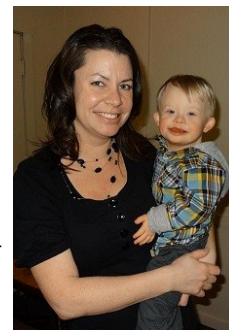
Besides the daily therapy and monthly specialist appointments, we live our lives just as any "typical" family does. We have the same concerns, hopes, dreams, and fears as any other good parent has for their children. We understand that Casey will need more assistance throughout his life, but we look forward to his future just as much as we do for his brother.

If you are lucky enough to be in Casey's life, you have this amazing feeling that is almost indescribable when you are around him. His smile and laughter can make you so happy



that it's almost as if you were living a beautiful dream. He loves to see people smile, and in turn, ALWAYS smiles back. His double-handed wave is just the cutest. And boy is he a kissing fool. He loves to give kiss after kiss after kiss, and even makes a kissing noise while doing so. Not to mention his love for kissing the animal characters on his footie pajamas every night!

Casey adores his brother! I catch him staring at Blake a lot. One of my favorite things is to hear their cheerful laughter while they are playing a funny game together. Blake loves Casey. He began calling him Cici when he first learned to talk and it stuck with all of us. When Casey is fussing or crying about something, I ask Blake to make him laugh and he succeeds EVERY time! Blake gets proud of Casey just like mommy and daddy. He encourages his brother and sometimes helps him a little too much. On the rare occasion that the boys and I are not all together and I just have Blake, Blake becomes very concerned and continuously asks where Cici is. The bond that these two have is incredible.



When I think about the past, and relive my fear of the unknown, I wish I could have fast-forwarded and seen a 30-second video of our 2 ½ year old Casey as he is today. He is 100% absolutely amazing in every aspect of his being. I would not change a single thing about him! When we walk into Casey's room in the morning, we don't see Down syndrome. We see Casey! Our dimple-smiling, beautiful, brave, Casey. One of the two loves of our lives!!!!!!

The Boyer Family



Apply for Summer Scholarships before the May 31st Deadline

This newsletter includes an insert for the FEDS Summer Scholarship application. Your donations and participation in FEDS fundraisers made these scholarships possible. If you are a member, please apply on behalf of your child with Down syndrome. All FEDS asks in return is a picture of your child engaged in the scholarship activity and a brief thank-you note or short article for the newsletter. All applications must be received by May 31st to be considered.

D.A.D.S. Needs Your Help

The D.A.D.S. group needs your help to make their 3rd Annual Golf Outing a success. Right now, the group is in dire need of hole sponsors, items for the raffle, and/or donations. Please use your family, friend and business contacts to give the dads of D.A.D.S. a hand.

Of course you can also help by signing up a foursome for the outing or volunteering to help the day of the outing.

If you think you can help, please contact Jim Spencer at jspencer50@msn.com or 586.596.4104.

Education: The New Rising Stars Academy is Accepting Registrations

This information was provided by Mark Prentiss (586-202-9466), a co-founder with his wife Deborah of Rising Stars Academy, a new post-secondary school that will open later this year. The school is currently accepting enrollments. More detailed information is on the website at <http://www.risingstars2013.com>. The following is a copy of a letter that was sent to the special education departments of area school districts.

Rising Stars Academy is opening this year and will provide a new innovative learning opportunity for your students who will need continued education after high school. Please take a moment to look at our website to see specific details of our program - but in a nut shell we are:

A life skills, employment center that focuses on the world of food. Our students will grow their own food in the community garden while learning how to be a part of that community and honing their social skills. Students will then harvest that food and bring it to the kitchen to prepare it to serve to the guests in the on-site restaurant. Half of each day will be spent next to job coaches in areas food establishments learning job skills. Our students will also have classes in money management, citizenship, communication and developing positive relationships etc.

What's different about our program....we have built a community around our school of businesses, farmers, restaurants, organizations that see the value of the "community" connection that we are making. This community connection will help our students learn how to become a viable member of the community thru continued support which we feel is vital for their becoming sustainable, future community members.

Our website tells our story - that is based on a passion to help the growing number of these students become successful. We are a NON-profit school that has partnered with other non-profits to help serve these students. You will find our curriculum guide, student handbook, brochure along with all of the forms necessary to register a student.

Please provide this to your parents as an option for their students. They can contact us thru the website or via the information below. Our building is under construction but we will have afternoon/evening office hours beginning in two weeks. Consult the website for dates and times.

We would love to come out and meet you in your district. If you choose, we can set up an appointment.

Thank you

Deborah Prentiss
Administrator
risingstar.prentiss@gmail.com
586-405-9473

Summer OT Group

This flyer was submitted by one of our members for distribution to our members. FEDS is including it here as a service to members who may be interested in summer occupational therapy for their child. Its inclusion should not be considered as an endorsement by FEDS. A FEDS summer scholarship could be used to help cover the fee for this class.

Handprints

An occupational therapy group for children with Down Syndrome designed to develop and master skills for independent living. This summer, we are offering 2 sessions of Handprints- one for older kids and one for younger kids!!

Tuesdays at 11:00
June 25- August 20
No Class July 2
Ages 8-10 years

This group will focus on building strength and coordination for manipulating fasteners on clothes, mastering utensil and tool use, and strengthening hands for handwriting.

Tuesdays at 3:00
June 25- August 20
No Class July 2
Ages 3-6 years

This group will focus on building strength and coordination for opening and closing things, picking up and releasing toys of various sizes, manipulating knobs and buttons and experimenting with crayons and utensils.

Beaumont Health Center
Royal Oak
Cost is \$143 for 8 weeks

***If you have any questions, please contact Megan at 248-655-5660 ***

Belated Mother's Day Encouragement from the Love and Logic Insider's Club

Moms...do you ever feel like the weight of the world is resting firmly on your shoulders? Do you ever feel like it's your job... YOUR JOB... to make sure that your kids always do the right thing and turn out well? Do you ever worry that the entire neighborhood is aware and judging you when your kids sneak out of the house with mismatched socks, messy hair and less-than-polite attitudes?

Oftentimes, the most loving and effective mothers take the most heat from others and themselves.

Wonderful moms understand that kids need to make plenty of small, affordable mistakes. They know that kids must experience occasional struggles and disappointments. They also know that constant rescuing or micromanaging just creates kids who need constant rescuing and micromanaging.

Because of this, the best moms often feel a bit lonely and unsure of themselves. They feel lonely because our society too frequently rewards what looks good rather than what is good. They feel lonely because they rarely overhear other mothers bragging about allowing their kids to learn by forgetting a lunch, misplacing an occasional homework paper, or having to pay for a lost coat.

The best moms often feel a bit lonely and unsure of themselves.

It's easy to feel guilty or insecure when you see so many "super hover mommies" acting like pack mules, carrying all of their children's sporting equipment, back packs and other responsibilities. It's easy to lose perspective when your minivan is the only one without an "Honor Student" bumper sticker. It's tempting to waver when the parents next door are working harder completing their child's homework than their child is.

On this Mother's Day holiday, I hope to encourage all of the wonderful mothers who let things fall apart from time to time...who understand the wisdom of providing a rather imperfect world for their kids. When you find yourself feeling insecure or guilty, listen to our audio, [*Helicopters, Drill Sergeants and Consultants*](#), and be reminded that it's far better for our kids to submit a sloppy science fair project than them seeing us hunched over the kitchen table frantically doing it for them.

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

Dr. Charles Fay

Reprinted, with permission, from the Love and Logic Insider's Club tip of May 8, 2013.

Special Olympics News

YAP is wrapping up another successful school year. We hope our young athletes find lots of activities to keep them busy this summer, and return ready to participate in the fall.



The FEDS Bocce Team participated in the Macomb Area Local Games on May 7th at Macomb Community College. The weather was beautiful, the grass was mown short, and the athletes had a great time.

GOOD LUCK to the bocce team members and the other FEDS athletes who will participate in the Special Olympics State Summer Games in Mount Pleasant on May 30 to June 1.

Ten Tips for Siblings of Persons with Intellectual and Developmental Disabilities

- 1. Prepare:** If you're eventually going to be a co-pilot in your sibling's life, you've got to earn your wings, right? If you can, take time before you take over your parents' role to learn about important aspects of your sibling's life, including what support services, networks and legal pieces already are in place.
- 2. Seek help and ask Questions:** No one said being a sibling is easy! Make sure you're getting the support and information you need. Don't be shy — ask others in your life to contribute by helping your sibling budget or grocery shop or just being there to listen to you.
- 3. Meet Your Sib's network:** There are likely many people involved in your sibling's daily life whom you haven't met. Host a "meet & greet" to get to know who supports your sibling professionally and other people who are important to your sibling, such as friends and other community members.
- 4. Create a network for Yourself:** Believe it or not, there are thousands of siblings walking in your shoes. Through local advocacy groups or provider organizations that support or care for people with disabilities, find other adult siblings to share ideas and feel supported. Check out www.siblingsupport.org to get started.
- 5. Get to Know the Pros:** Get to know your parents' advisors. Finding experienced professionals such as guardianship attorneys, financial planners and medical professionals can make your job easier.
- 6. Dream big:** If your sibling has not had an opportunity to be involved in Person Centered Planning, find a resource to make that happen. You can support your sibling to live a great life focused on her goals, interests, hopes and dreams. Giving direction and focus to your sibling's life will make your role as guardian or support system easier.
- 7. Involve Your Sib:** Think about ways to keep your sibling involved in making decisions and stay focused on his goals.
- 8. Keep Your Sib role:** Try to maintain the special bond as a sibling. Get the necessary help and support so the sibling role is not completely replaced by the caretaker role. Remember to have fun with your sibling and involve her in your life as much as you want to or are able.
- 9. Develop Your own Style:** You're not your parents and you have your own special relationship with your sibling. Remember that your parents had a steep learning curve, too, and you don't have to do everything the same way they did! You may have new ideas, plans and opportunities to work with your sibling to enable him to have new experiences and a fun-filled life.
- 10. Take Care of Your Dreams:** Don't let your own dreams die in the process of helping your sibling realize her dreams. Have someone be your "check and balance" and help you when you get overwhelmed or your life gets out-of-balance in caring for your sibling

Reprinted from Down Syndrome News, Volume 34, Issue #4, a newsletter of the National Down Syndrome Congress, 1370 Center Drive, Suite 102, Atlanta, Georgia 30338, ndscenter.org



Upcoming Events

Moms Night Out

Thursday, May 23, 2013
7:00 pm

Twisted Rooster
45225 Marketplace Blvd.
Chesterfield, MI 48051
(at M-59 and I-94)
586-949-1470
<http://www.twisted-rooster.com>



Please RSVP to Angela at
angela-gallihugh032912@gmail.com

When you RSVP and let us know this is your first
Mom's night, your meal will be on us.



D.A.D.S. Meeting

Wednesday, May 29, 2013
7:00 pm

Club Venetian
29310 John R Road
Madison Heights, MI 48071

Join us for dinner, conversation, and info on the golf
outing. Dads, uncles and grandfathers
welcome.

3rd Annual D.A.D.S. Golf Outing

Saturday, July 13, 2013
1:00 P.M.

Boulder Pointe Golf Club
Oxford, MI

Now is the time to get your foursome together.

Non-golfers are invited to enjoy all the festivities and
join us for dinner.

More information is available at the D.A.D.S. meeting,
or contact Jim Spencer at
jspencer50@msn.com or 586.596.4104.

ANNUAL MEMBERS PICNIC

Save the Date

Our summer picnic will be on **Saturday, August
3rd at 11:00 am**. It will be held again at the Vet-
erans Memorial Park in St. Clair Shores on Jef-
ferson. Look for details as the event gets closer.

Volunteer

Many volunteers will be needed for this event,
including set up, clean up, prizes and grilling.
Contact Sheryle with your volunteer preference.

RSVP

Please RSVP to Sheryle by July 20th so that we
can plan on prizes and food. Please indicate
how many children will be attending, and their
ages and genders.

To volunteer or RSVP, please contact Sheryle
Fournier at sherylef09@hotmail.com

"Alumni" Moms Night Out

The next "Alumni" Moms Night Out will be in July.
More information will be sent when available.



Families Exploring Down Syndrome

PO Box 1191

Sterling heights, MI 48311



FAMILIES EXPLORING DOWN SYNDROME

WISHES EVERYONE

A SAFE AND FUN SUMMER