

Down Syndrome Family Support and Advocacy Group Newsletter

December 2011



The Twelve Days of Christmas



On the first day of Christmas, the good Lord gave to me: a child with a disability.

On the second day of Christmas, the good Lord gave to me: a heart full of love for my child with a disability.

On the third day of Christmas, the good Lord gave to me: an ache in my heart and a heart full of love for my child with a disability.

On the fourth day of Christmas, the good Lord gave to me: a tear in my eyes, an ache in my heart and a heart full of love for my child with a disability.

On the fifth day of Christmas, the good Lord gave to me: an unsuspected strength for the tear in my eyes and the ache in my heart and my heart full of love for my child with a disability.

On the sixth day of Christmas, the good Lord gave to me: a ray of hope, an unsuspected strength for the tear in my eyes and the ache in my heart and my heart full of love for my child with a disability.

On the seventh day of Christmas, the good Lord gave to me: a sense of humor, a ray of hope, an

Continue page 2

In this Issue Page

Poem 12 Days of Christmas	1 - 2
Winter Party	1
Specs for Us	2
United Way/Company Match	3
Newborn to 3yr Parent Meeting	3
DS Teen/Adult Night	3
4 to 7yr & 8 to 12yr Parent Meeting	3-4
Dr Skotko	4
Calendar of Events	4
DSFSAG Directory	5
Lending Library	5-8
2011 Walk for Down Syndrome	6
Thank You Sponsors	6-7
Thank You Gates/Toyota	7
Research Talk - Mike Mannor	7
MNO - Laporte, Marshal & St. Joe, MI	8
Birthday Greeting	8

Winter tubing Party



Date: February 4, 2012

Time: 12:00pm to 4:00pm

Place: Ferrettie/Baugo Creek

57057 Ash Road, Osceola, Indiana 46561

RSVP: Anne- artrevell@aol.com

574-243-3808

Kathy - kratkiewicz@gmail.com

574-234-0590

Potluck lunch served at 12:30pm

Main dish, tableware and soft drinks provided by the Group. Please bring a dish to share.

There will be tubing after lunch for all those who want to participate and then come back for some hot coco. All ages welcome to attend-you don't have to tube-we have a heated, indoor room by the tubing hill where you can relax, eat, and the kids can do a craft.

For directions go to:

<http://www.sjcparks.org>

unsuspected strength for the tear in my eyes
 and the ache in my heart and my heart full of
 love for my child with a disability.

On the eighth day of Christmas, the good Lord
 gave to me: supportive friends, a sense of
 humor, a ray of hope, an unsuspected strength
 for the tear in my eyes and the ache in my heart
 and my heart full of love for my child with a
 disability.

On the ninth day of Christmas, the good Lord
 gave to me: remarkable doctors & therapists,
 supportive friends, a sense of humor, a ray of
 hope, an unsuspected strength for the tear in
 my eyes and the ache in heart and my heart full
 of love for my child with a disability.

On the tenth day of Christmas, the good Lord
 gave to me: an appreciation of small
 accomplishments, remarkable doctors &
 therapists, supportive friends, a sense of
 humor, a ray of hope, an unsuspected strength
 for the tear in my eyes and the ache in my heart
 and my heart full of love for my child with a
 disability.

On the eleventh day of Christmas, the good Lord
 gave to me: a sense of pride, an appreciation of
 small accomplishments, remarkable doctors &
 therapists, supportive friends, a sense of
 humor, a ray of hope, an unsuspected strength
 for the tear in my eyes and the ache in my heart
 and my heart full of love for my child with a
 disability.

On the twelfth day of Christmas, the good Lord
 said to me: Reach out and share your sense of
 pride, your appreciation of small
 accomplishments, your remarkable doctors &
 therapists, your supportive friends, your sense
 of humor, your ray of hope, your unsuspected
 strength for the tear in your eyes and the ache
 in your heart and your heart full of love for your
 child with a disability.

(Author Unknown)



13571 W. Spring St, Burton, Ohio 44021
1.800.586.1885

SPECS4US, Superior Precision Eyewear for Children Who Are Special, introduces a new concept in eyewear for children with Down syndrome that eliminates the problems commonly associated with traditional eyeglasses. The mission of SPECS4US is to improve the vision and quality of life for individuals with Down syndrome by providing affordable custom frames designed especially for them.

The Erin's World line of frames is engineered to fit the unique facial features of children with Down syndrome while offering stylish options handcrafted for an active lifestyle. Each pair of frames offers special design features not found anywhere else. Adult sizes and sunglass clips are also available.

Created by the mother of a child with Down syndrome and 25 years experience as an optician, the Erin's World eyewear from SPECS4US will help children and adults explore their world with enhanced vision combined with an exciting level of style.

You can find the Erin's world line of frames at:

RX Optical
1700 S Park Street
Kalamazoo, MI 49001
269-342-0003

For more information and additional locations, visit www.SPECS4US.com or call 1.800.586.1885.

Locally they are carried at:

The Eye Care Associates of Michiana
17477 Generations Drive, South Bend, IN
574-287-0890

United Way/Company Match

When providing a donation at the time of the Walk for Down Syndrome or throughout the year, don't forget to ask your employer if they do a **company match**. A number of companies will match your donation partial or in full. If your company is willing to do a company match, please fill out the appropriate paperwork to have them send their donation directly to DSFSAG. This is a great opportunity to make your personal donation grow and allow us to continue to support our efforts in the community.

Do you give to the **United Way**? If so, do you realize you can donor designate to the Down Syndrome Family Support and Advocacy Group, Inc. When completing your United Way pledge card, indicate you would like to donor designate. Our agency account # is 737438. Please think about having your full or partial United Way contribution help us continue our mission to help improve the lives of individuals with Down syndrome and their families through education, advocacy, research, and fellowship.

DS Teen + Adult Night

On the 3rd Friday of the month we are having a fun night out for our teens (13+) and adults with Down syndrome. Check our web site or look for updates on the listserve for the places that we will be meeting at each month. Time will be from 6:00 pm till 9:00 pm. We will provide dinner and drinks.

There will be other typical peers that will volunteer to hang out and have fun; we will also have adult volunteers/supervision.

Our next DS teen/adult night will be **January 20, 2012 please RSVP to Anne Revell** artrevell@aol.com or 574-243-3808 or Kathy Ratkiewicz kratkiewicz@gmail.com or 574-234-0590.

Upcoming Dates:

February 17, 2012	March 16, 2012
April 20, 2012	May 18, 2012
June 15, 2012	July 21, 2012

Birth to 3yrs Parent Meeting



Families who have a child between the ages of newborn to 3 yrs are invited to attend our new monthly parent get together. We are going to try to have them on the last Wednesday of the month (in a month where a holiday conflicts, we will work something else out) Since these will likely be fairly small meetings, children are welcome to attend...we will have toys available, but at this point, we will not have childcare. (The room is small enough that we can watch them while we visit with each other)

This month's meeting will be **Wednesday, January 25th, 2012** at 6:30 pm. light refreshments will be served. Janet Lovett, Speech and Language Pathologist, will give a talk on ways to prepare children with Ds for speech. Please RSVP Kathy At: kratkiewicz@gmail.com or 574-234-0590.

Upcoming Dates:

February 29, 2012	March 28, 2012
April 25, 2012	May 30, 2012
June 27, 2012	July 25, 2012

4 to 7yrs & 8 to 12 yrs Parent/Child Group

We are hoping to expand our current monthly family support meetings to include a 4-7yr old group and an 8 to 12yr old group. These meetings would give parents and kids of similar ages a chance to get to know each other. Since the groups are smaller the meetings could be held at the Center. Once the meetings begin, parents could discuss if they would like to have some of the activities outside of the Center. Some examples of this could be going to a movie, Chuck E Cheese, Mega Play, etc.

The group will budget for these meeting so there will be no or very little cost to families.

Continue page 4

Sue Pearson is planning on being one of the planners for the 8 to 12yr old group; she would like to take the last Friday of the month. She will have the first official meeting on Friday January 27th, 6:00pm at the center as a planning meeting for parents with a movie and popcorn for the kids. Please RSVP to her if you and child would like to attend: 574-299-3235 stpearson@sbcglobal.net

January 27

February 24

March 23

April 27

May 25

We need to know if there is any interest in a few others who would like to participate and help plan these smaller support groups. We are in need of a lead planner for the 4 to 7yr old group. If you're interested please contact Kathy at kratkiewicz@gmail.com or 574-234-0590.

Dr. Skotko

We (DSFSAG) are in the final stages of planning to bring in Dr. Brian Skotko (BrianSkotko.com) to speak on **Prenatal and Postnatal diagnoses of Down Syndrome: New advances and Updates for Today's Physicians** at Grand Rounds at Memorial Hospital on February 22, 2012 and a Mini-Medical School at the IU Medical School at Notre Dame on the evening of the 22nd.

Additionally, we are planning for Dr. Skotko to give the following presentation: **Healthy Students with Down syndrome: All the Medical Updates that Educators Need to Know**. This is geared towards parents, educators, therapists, etc, and will be held from 11 am to 1 pm February 23, 2012 at Logan Center

As soon as the details are finalized, I will update everyone with the specifics. However, if anyone has any questions, please feel free to contact me druandemily@sbcglobal.net

Calendar of Events

- Jan 10 - MNO place TBA
- Jan 11 - Research Talk @ MDSR Center
- Jan 20 - Teen + night, Place TBA
- Jan 25 - Birth to 3 @ center with Janet Lovett
- Jan 27 - 8 to 12yr old group meeting @ MDSR Center
- Feb MNO - TBA due to Valentine's Day
- Feb 4 - Winter Tubing Party, Baugo Creek
- Feb 17 - Teen + night, place TBA
- Feb 22 - Dr.Skotko will speak at the Mini Med School at the IU School of Medicine at Notre Dame
- Feb 23 - Dr Skotko will give a presentation to parents and professionals at Logan Center
- Feb 24 - 8 to 12yr old meeting , place TBA
- Feb 29 - Birth to 3 meeting @ MDSR center
- March 13 - MNO Place TBA
- March 16 - Teen + Night place TBA
- March 21- World Ds Awareness Day
- March 23 - 8 to 12yr old meeting, place TBA
- March 24 - Annual Resource and Transition Fair at IUSB
- March 28 - Birth to 3 meeting @ MDSR center
- April 10 - MNO place TBA
- April 20 - Teen + Night place TBA
- April 25 - Birth to 3 meeting @ MDSR center
- April 27 - 8 to 12yr old meeting, place TBA
- May 8 - MNO place TBA
- May 18 - Teen + Night place TBA
- May 30 - Birth to 3 meeting @ MDSR center
- May 25 - 8 to 12yr old meeting, place TBA
- June 12 - MNO place TBA
- June 15 - Teen + Night place TBA
- June 27 - Birth to 3 meeting @ MDSR center
- July 10 - MNO place TBA
- July 20 - Teen + Night place TBA
- July 25 - Birth to 3 meeting @ MDSR center

Please refer to our web site or the listserv for more information on place and time of some of the events listed. If you do not have computer access and are interested in one of the events please call Anne at 574-243-3808 or Kathy at 574-234-0590

www.michianadownsyndrome.org

MNO = Mom's night out

TBA = To be announced

MDSR Center = Michiana Down Syndrome Resource Center at 2400 Miracle Lane, Mishawaka, IN 46545 (Town & Country Shopping Center)

DSFSAG Directory!

We are in the process of organizing the updated version of the DSFSAG directory! We hope to increase the participation from the 2008 directory, and one of the changes that may address the privacy concerns that some may have is the option to omit either your address, your phone numbers, or both. We hope that you may consider being a part of this directory, if only with your name, as this is a resource guide for and directory of our community, and not merely a phone book. There is truly advocacy and support, as well as strength, in numbers - especially for our newer families.

Other changes we are proposing for the new directory is an inclusion of siblings and their ages (just years, and not birthdays - again for privacy's sake). This may not only help with play dates and sibling support groups, but it also emphasizes that we are a community of families, and not just individuals. Formatting changes will also allow for multiple emails and cell phone numbers. As the signup sheet at the Walk had limited success (with both participation and legibility), we ask that in order to be included in the directory, please contact Rick Podrasky by March 1, 2012 at rpodrasky@gmail.com with the following information: Family name and heads of household, address (optional), home telephone (optional), cell phone(s) (optional), email(s) (optional), child (plus age), and siblings (plus ages) (if applicable). If email access is an issue, you may also call or mail the information to the Resource Center (again, by March 1, 2012).

In addition to the new format - and the inclusion of new families - we would like to introduce the inaugural cover art contest! We would ask that 5"x5" pen or pencil drawing (limited to black and white, as that is how it would be printed on the cover) entries be submitted to the Resource Center by March 1, 2012. There isn't a specific theme other than celebrating the talent of those in our community, so the more entries - the merrier!

Lending Library



Our Lending Library is located at the Town and Country Shopping Center at 2400 Miracle Way, Mishawaka, IN 46545. Please call us to make an appointment to come in as we are 100% volunteer organization and at this time do not have any scheduled hours.

Anne 574-243-3808 artrevell@aol.com

Kathy 574-234-0590 kratkiewicz@gmail.com

New Library Items

- ❖ Baby Genius DVDs
 - A Trip to the San Diego Zoo
 - Animal Adventures
 - Favorite Children's Songs
 - Favorite Nursery Rhymes
 - Favorite Sing-A-Longs
 - Mozart and Friends
 - Mozart and Friends Sleepy time
 - Underwater Adventure
- ❖ Booty Camp Potty Training Program
- ❖ The Kitchen Classroom: 32 Visual GFCF Recipes to Boost Developmental Skills
- ❖ It's Potty Time! DVD by the makers of Signing Time
- ❖ Kaufman Speech Praxis Kit: The Kaufman cards are ideal for building motor-speech coordination for children with apraxia of speech.
- ❖ Down Syndrome Parenting 101-Must Have Advice for Making Your Life Easier
- ❖ What's Eating Your Child? The Hidden Connections Between Food and Childhood Ailments: Anxiety, Recurrent Ear Infections, Stomachaches, Picky Eating Rashes, ADHD and More. And What Every Parent Can Do About It
- ❖ Teach2Talk DVDs(partial list)
 - Action verbs, Intermediate Play, Where?
 - Body Parts, Who? Behavior with Friends
 - Prepositions.

Continue Page 8

2011 Michiana Walk for Down Syndrome

This year's Annual walk for Down Syndrome was another huge success by meeting our goal of \$40,000. This event brings awareness of people with Down syndrome and shows others in the community what joy and happiness they bring to us. For the past ten years this walk has been a big event for the kids and their families to get together and have a good time.

The kids loved to play all the games with all kinds of wonderful prizes to win. The duck pond, fishing, bowling, putt putt are some of the games the kids loved to play.

Entertainment by Leonardo is always a welcomed event. From all the silly songs he sings, he really gets the kids involved. The way the band interacts with the kids is fabulous. From dancing with the kids, allowing them to play instruments, and singing it is definitely entertaining for all

This year ND let us extend the walk to the football field. There was a lot of excitement to get the walk started so everyone could spend time on the football field. Many pictures were taken and several ND athletes were there to interact with the kids. Nothing but smiles and laughter were expressed as walkers made it back to the Stepan Center where refreshments were served.

As you can see the day was filled with lots of fun and entertainment. Thanks goes to all the volunteers and sponsors that make the walk a great experience for all.



We cannot express our gratitude enough to all of our sponsors who donated to our walk this year! You are the reason our walk was a success!

Thank you!

2011 Walk sponsors 2500+

Midwest Orthotics
SureStep



2011 Walk Sponsors \$500+

Advanced Ophthalmology
Bonefish Grill
Cardinal Fitness
Downunder Reef Pet Shop
Gates Automotive
Key Lime Cove
Lighthouse Car Wash
LOGAN Center
Mahoney Family Dentistry
Masters Styling Salon
Nathan Ratkiewicz
Notre Dame Athletic Department
Outback Steakhouse
Teachers Credit Union
The Louvered Door



Food Sponsors

Boy Scouts troop 664/New Carlisle
Jersey Mikes
Penn Station
Pepsi
Revell/Banes Electric

General Walk Sponsors

Anointed Beauty Salon & Day Spa
At Home Realty Group
Build-A-Bear
Carrabba's
Charming Charlies
Children's Museum
CiCi's Pizza
Country Inn and Suites
Dairy Queen
Family Video
Five Guys Burgers & Fries
Hacienda
Inn at St Mary's
John Ratkiewicz - Lighthouses
John Unsicker
Karen Rieth - Scentsy Consultant
LaSalle Grill
Linda's Camp K-9
Marla Murasko
McDonalds
Mega Play
Mike's Car Wash
Moe's
Nutrition Now - Juanita & Tom Myers
Panera Bread
Potawatomi Zoo
Putt Putt Golf & Game
Regal Lanes
Ricky Schott
Rossini's Pizza
Salon Nouveau
Salon Rouge
Six Flags
St. Clair Apparel
Strikes & Spares
Tammy Sues/Michiana Bobcat
Target
The Kelly Family
TLC Upholstery
T-Nails & Spa
USA Skate Center
Vogue Beauty College
Wal-Mart



Thank You to Gates / Toyota and Their Employees!



Due to a major campaign by Ray, Laura and RJ Conley, our group will be receiving donations in the form of monthly pay roll deductions from 40 Gates employees! The employees were offered the opportunity to donate to local groups directly instead of to United Way, and Ray suggested our group...and the employees really came through!!!

See yearly totals below:

2012 Employees donations = \$5,198
Gates Gift = \$2,500
Toyota Gift = \$2,500
Total= \$10,198.66

Ray has been working on this for several months. In addition, due to a combined effort on the parts of Vicky Bavar and Ray, Gates also donated \$500 to our Walk this year! If anyone has the opportunity, please help us say thank you to Gates/Toyota for this awesome gift!

Thanks again, Ray for having the idea to put our name in for this program and for the awesome follow-up efforts!

Research Talk

On January 11th Mike Mannor has volunteered to give a presentation about some very exciting developments in cognitive research on Down syndrome based on research from Stanford and Johns Hopkins universities. This will be at the center starting at 6:00pm. We have limited space so we are not able to offer child care. Please RSVP if you plan to attend to:

Anne 574-243-3808 or Artrevell@aol.com

MOM's Night Out

Please keep an eye out on our website or on the listserv for future MNO's in LaPorte and Marshal Counties in Indiana and St. Joe County in Michigan. If you are interested in attending these fun evenings of good food, laughter and sharing please contact us for further information about these upcoming MNO's.

Kathy - 574-234-0590 kratkiewicz@gmail.com

Birthday Greetings

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

Lending Library continued

The following excerpt is from **Down Syndrome Parenting 101-Must Have Advice to Make Your Life Easier** by Natalie Hale (available for checkout from our library)

"What is true is that I believe that almost all children with Down syndrome can learn to read. When there are multiple diagnoses involved, reading can get dicey, and in isolated, very challenging cases, reading may be quite limited: but I've seen too much success to immediately label anyone as unteachable when it comes to literacy. "Snip

"If (your child) enters kindergarten already reading, the school's expectations of him will skyrocket." end quote.

The rest of the chapter is devoted to details on how to make your child (or adult with Ds) a reader.

DSFSAG
51201 Old Cottage Dr
Granger, IN 46530

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