

Down Syndrome Family Support and Advocacy Group Newsletter

August 2009

An Extra Little Chromosome

By: Debbie Gibson

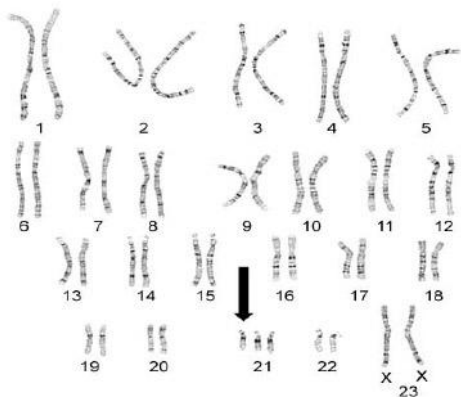
An extra little chromosome,
that's all it is, you see.
Where all of you were born with two,
I was blessed with three.

Down syndrome as most call it,
Trisomy 21, if you please.
This extra little chromosome
makes some differences, you see.

I love to run and sing and dance,
and tease my teachers too.
But when it comes to school work,
it's hard for me to do.

I need a little extra help,
as many of you do.
With all my friends and your support,
I know I'll make it through.

Just be my friend,
and I'll be yours.
It's as simple as can be.
Remember, you were born with two,
and I was blessed with three.



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Michiana Walk For Down Syndrome

By participating in the Michiana Walk for Down Syndrome you help bring Awareness, Resources, Support and Advocacy for all those with Down syndrome and their families who live in the Michiana community. We are a 501(c)3 tax-exempt and 100% volunteer organization. All gifts are tax-deductible to the extent permitted by law. All funds raised will go towards:

- Grants to help with medical or educational needs
- Scholarships for a person with Down syndrome to attend higher education
- New Parent Information & Resource Packets
- School transition packets
- Hospitalization get-well bags
- Support for research and advocacy
- Financial assistance for developmental/recreational activities
- Educational Conferences & Parent Support Groups
- Mom's Night Out, Family Parties, gatherings and much more

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Walk Continued

Take your brochure everywhere you go, to the office (ask your employer to provide a matching gift donation), to the gym, to your place of worship and to your neighbors "OR" get donation ONLINE at <http://www.firstgiving.com/mds> Click on the "Get Started" link. You can register your team or you can register as an individual walker. With this site, you are able to create your own fund raising page and easily reach out to others to ask for their support. We also except check or money orders please make your tax-deductible checks payable to: DSFSAG or Michiana Down Syndrome.

Go team!

Create a team to support an individual with Down syndrome. Collect donations online or in person. Each team receives a sign to carry at the walk. The team that raises the most money will have their team photo on next year's brochure, in the calendar and on our website. For every \$50 a team earns, the captain receives a t-shirt to distribute to team members who will be present at the Walk. We do not have enough t-shirts for those who do not participate in the walk.

Team Captains or another team member can bring in your donations and pick up T-shirts for those who will be walking. **To compete to win** you must turn in all signed waivers for those who will be walking, your check, money orders, cash and a printout of your online donation to **registration... Registration staff will not have a running total for Teams, Teams need to present their totals at one time**, it is up to you to have all funds added and present them altogether at registration.

10:00am **OPEN:** Registration, silent auction, raffles, vendor tables and fun activities for the kids

10:00 - 11:00 Leonardo performs

11:00 -11:30 Dance group

11:30 **CLOSE:** Registration, silent auction, raffles & vendor tables

11:35 Commencement speech

12:00 Walk - 12:30 Lunch following Walk

12:30 - 1:30 Leonardo's 2nd performance

12:30 - 1:30 vendor tables open again

*** Fun activities for the kids plus Meet with Notre

Dame Athletes throughout the event



Mini Grants Service Hours

The Down syndrome Family Support and Advocacy Group (Michiana Down Syndrome Group) has decided to add a new requirement to our \$200 mini grant that all our members are currently eligible to apply for. Due to the growth of our group which is 182+ families strong, we are in need of more volunteers during our events. In order for us to be able to provide all the wonderful services and enable us to add more in the future, we need support from our members. Volunteering for the group builds a stronger community through fellowship as we all work towards a common goal of improving lives of people with Down syndrome. The DSFSAG is just asking for your help at one event or function per year (minimum of 2 hours). There are many areas in which the group needs help (DS walk, Old 2 Gold, hot dog sale, committees, family support nights, helping with parties, fund raising to name a few).

From September 1, 2009 through Dec 31, 2010, please bring the DSFSAG Service Documentation Form with you when you volunteer for any DSFSAG function or event. See attached form. A board member will sign off on the form verifying your service at the event. Starting in January, 2010, mini grant applications will need to include the grant application, receipts and the new volunteer service verification form.

A couple of rules regarding service:

Event volunteer service hours can be saved and used from September of previous year through December of the year the application is submitted. Event volunteer service hours given for one event cannot be split and used for two grant applications. There will also be a limit of volunteer hours per event, so sign up quickly for an event you would like to work to guarantee your hours.

Lending Library



Check out

<http://www.michianadownsyndrome.org/DS%20Web/library.htm> for a list of our library materials housed at Logan Center. Items from the library can be checked out for a period of 3 weeks. Here is a sample of just one of the many books we have.

Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome (Paperback, 2 copies)

This comprehensive resource guide for educators and parents provides facts and strategies on dealing with health, communication, cognition and behavior, curriculum adaptation and a host of other topics.

Scentsy Candle Fundraiser

Hello, I'm Robin Wolford and I'm hosting a Scentsy Fundraiser for the Down Syndrome Family Support and Advocacy Group, 15% of the proceeds will go to the group.

Scentsy Wickless Candles have no flame, soot or wick, the Scentsy system is a safe way to enjoy more than 80 Scentsy fragrances. As a mother of a child with special needs, I especially like the safety aspect of not having a lit flame.

To view our products you can go to my website www.scentsy.com/robinw. Anyone who would like to have a party in their home, have a basket party at their place of business can contact me by e-mail at nowickcandles@comcast.net or call me at 574-360-5325 and I will be happy to get this started for you. The Scentsy Fundraiser for the DSFSAG will be from May through October 15, 2009.

I will have my Scentsy Table at the Walk on Sept 26th so can sample all the wonderful fragrances of the Scentsy Wickless Candles. I will also be putting a Scentsy basket in for the auction. Again 15% of all the proceeds go to the DSFSAG.



Join Our Online Listserv To Keep Up to Date On All Of Our Current Events!

If you are not a member of our yahoogroups listserv yet, please consider joining. It is a convenient and free way to keep in touch with what is going on with the group as we talk about upcoming events, news of the day, legislative efforts, ask for advice from other parents, etc.

<http://health.groups.yahoo.com/group/MichianaDownSyndrome> click on 'Join this Group'

Facebook

Kirk Goodwin has set up a Facebook for the group. To join, go to: <http://tinyurl.com/DSFSAG>. If you are already a member of Facebook, you can then log into your account and request to join the group. If you are not a member of Facebook,

- 1.) Create a Facebook Account
- 2.) Log into your account after checking the "Remember me" book (you need to be first logged into Facebook to make the links work).

Current Events

September

- Tuesday 8th Mom's Night Out 6:30pm at Hacienda on Portage
- Saturday 26th Michiana Down Syndrome Walk (Formally known as the Buddy Walk) September 26th University of Notre Dame, Stepan Center. Fun starts at 10:00 am

October

- Tuesday 13th Mom's Night Out 6:30pm at Famous Dave's on Grape Rd
- Halloween Party, more info to follow

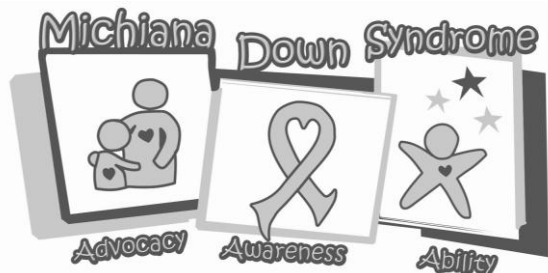
November

- Tuesday 10th Mom's Night Out 6:30pm TGIF on Ireland

December

- Tuesday 8th Mom's Night Out 6:30pm at Papa Vino's

Logo Contest Winner



(Logo colors not shown in this newsletter are royal blue and gold-yellow that can be view at our web site www.michianadownsyndrome.org)

This is our NEW LOGO. It's a combination of two winners, Jill Privett who entered the mother and child and Nathan Ratkiewicz who submitted the old logo with the colors changed to yellow and blue and he had added the awareness ribbon in the middle. When the board reviewed all entries and couldn't come up with one that "alone" stood for all we feel the group is about, we decided to combine two entries then came up with the idea of a star person. We asked Nathan to do a few more changes, we wanted to get rid of the noodle people and feet because we didn't see how they represented our group. So now here is the concept of our NEW LOGO.... It's in "3" parts to stand for "Trisomy" it has "3" symbols and under each symbol there is a mission of what we do and stand for, again "3" of them... and we can even count off 21 elements to this LOGO for Trisomy 21. We hope you all like this LOGO!

1. The color yellow
2. The color blue
3. The word Michiana
4. The word Down
5. The word Syndrome
6. The word Advocacy
7. The word Awareness
8. The word Ability
9. The image of the child
10. The image of the mother
11. The awareness ribbon
12. The star person
- 13, 14, 15. The 3 little stars
- 16, 17, 18. The 3 blue hearts
- 19, 20, 21. The 3 boxes

Thank you to everyone who took the time to be creative and enter this contest. We had some wonderful entries and it did not make our decision easy.
Thank you again!

Products Made by People with Down Syndrome and Others with developmental Disabilities

Gathered online by Colleen Reck, August 2009

A non-conclusive list of people with Ds that make or sell products available online. Please clip and save for gift giving time, whether it is for a birthday, holiday or teacher's gifts.

1. **Simply Adorable Blankets** is a successful business online, thanks to the artistry of three young women with Down syndrome. They just opened a unique store that will showcase the talents of six young adults with developmental disabilities.

<http://www.simplyadorableblankets.org/>

2. **Creekside Cookies and More** is a sister business to Simply Adorable. They sell baking mixes, preserves, sauces, soup mixes and gourmet & candied peanuts.

<http://www.creeksidecookiesandmore.org/>

3. **Rose's Rugs** is a business run by Rose Caplette, a 26 year-old entrepreneur from Bozeman, MT with Down syndrome. <http://www.rosesrugs.com/> A related article can be found here

<http://bozemandailychronicle.com/articles/2008/03/31/news/20rugs.txt>

4. **Waggies** are all natural peanut butter dog treats lovingly baked in Wilmington, Delaware by persons who have intellectual disabilities.

<http://www.waggies.org>

5. **True Meaning Jewelry** is a line of beautiful beaded jewelry that is handcrafted by special needs artisans, including adults with Down syndrome. Among the choices are awareness bracelets (DS, autism, diabetes, Alzheimer's, breast cancer, Cerebral Palsy and others) as well as Special Olympics (they have charms for different sports) and specialty jewelry (Mother/Grandmother appreciation, graduation, I.D. badge holders & children's & First Communion bracelets).

http://www.newenglandvillage.org/truemeaningweb/truemeaningjewelry_home.html

6. **Michael Jurogue Johnson** is an artist from Evanston,

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Products Made Continued

IL who happens to have Down syndrome. From his website, you can commission Michael to paint from a photograph you provide or you can choose one of the many from his website. He also sells note cards and posters of his art.

<http://users.psln.com/sharing/Michael/mainMichael.html>

7. **OTxpress Awareness Wristbands** are a trendy and positive way to X-Press all student's individuality. Included are the sayings Include, Inspire/Teach, I Can, Art Smart, Dream Big and Never Quit. These inexpensive rubber bracelets are a good way for student clubs to raise money for their group or club. This is a business endeavor of Zach Vincent's, a Chicago-area teen with Down syndrome who picked the positive messages along with his siblings and readies them to pack and ship for fundraisers.

<http://www.otoutcomes.com/OTxpress.html>

8. Dylan Kuehl of **DK Arts** is a visual and performing artist from Olympia, WA, making his mark as a dancer, drummer, Special Olympics gold medal winner and self advocate. On his website, he has works of art for sale, greeting cards, calendars, etc. <http://www.oly-wa.us/dkarts/>

9. **Bernadette Resha Putman** is an artist living in the Nashville, TN area. <http://www.bernadetteresha.com/index.htm> Along with online sales, Bernadette exhibits in numerous art galleries, art and craft shows throughout south east and attends many conventions throughout the United States showing and selling her work.

Transition Bags

It's time for school again and we want to remind all Parents that we offer Transition bags for families going through the school transition process. These bags will have an "All About Me Book" for you to fill in the blanks with information about your child to give to his/her teachers and program assistants. Some of this information will be things like family members, favorite activities, health considerations, communication, places he/she likes to go, Myths & Truths about Down syndrome and much more. We encourage all families to fill in as much information about your child and to include other information you feel would be helpful for a successful transition.

The transition bag will also include the Susan J. Peoples book "Understanding How Children with Down Syndrome Learn". We have found that many teachers and program assistants have not been specifically trained about children with Down syndrome; most training is general to all students with disabilities so we feel that this book is a great resource for you to have and share with anyone working with your child.

These bags are for transition from First Steps into preschool or they can also be used for older children going from elementary, middle school or onto High school. We also offer a transition packet for Adults.

If you are interested in one of these bags please contact Shelly Schultz at 574-674-6769 superpack@aol.com or Anne Revell at 574-243-3808 artrevell@aol.com .

We hope everyone has a great new school year!



Birthday Greetings

The DSFSAG is happy to announce that we have started a new tradition of sending birthday greetings to all who have Down syndrome on our mailing list. Unfortunately we don't have everyone's birthday date yet, if you would like to have your child or family member receive one of our birthday greetings please contact Tonya Albertson at 219-778-9049 or at bteatrp421@verizon.net .

We are excited to get these birthday greetings sent out every month so we can let everyone in our Down syndrome community know that we are thinking of them, how important they are to us and that we are celebrating their special day with them.

Thank you.



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Advertise Your Services

We have many talented members who offer a variety of skills, services or goods. So starting with the next newsletter, we are offering our members an opportunity to advertise in the newsletter. This is a great opportunity to broaden the ways we support each other. A business card size ad will cost \$25/year for members only and your ad will run for a year (approximately 3 to 4 newsletter).

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