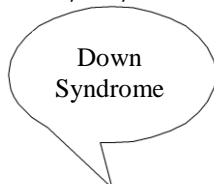


# Down Syndrome Family Support and Advocacy Group Newsletter

May 2009

## Two Words

by Cheryl Ward



Your birth brought us closer  
As death lingered near  
Your strength as you struggled  
Gave flight to our fear  
Down Syndrome they whispered  
days after your birth  
Two words that portrayed  
A false image of your worth  
Those words did not tell us  
Of the love you would bring  
Or the power your smile has  
To make our hearts sing  
Down Syndrome didn't tell us  
What kind of child you would be  
Filled with amazing surprises  
Shared with your father and me  
Hard work, determination,  
Teaching and learning, it's true  
Down Syndrome means much of this  
For each of us, not just you  
Wonder child, spirited child  
You've grown and you've thrived  
Your every achievement  
Still fills us with pride  
No matter the voice used  
Two words can't describe  
The fullness you've added  
To so many lives  
Down Syndrome, those frightening words  
Whispered so long ago  
Never did they prepare me  
For the person I now know.

## In this Issue

## Page

Two Words	1
Join our Listserv	1
ABLE Act	2
Lending Library	3
Fundraiser	3
2010 Calendar	3
Talent Show	4
Meet and Greet New Families	4
Current Events	5
Notre Dame Club News	5
Special Spotlight News	5
Birthday Greetings	5
Student Seeking Work	6
Advertise your service	6
Prenatal Awareness Initiative	6
Logo Contest	6

## 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).

## ABLE Act

February 26, 2009 Rep. Ander Crenshaw (from Florida) reintroduced legislation to create tax deferred savings accounts for individuals with disabilities. H.R. 1205 the Achieving a Better Life Experience (ABLE) Act of 2009, would amend the Internal Revenue Code of 1986 to provide for the establishment of tax deferred accounts – much like a “529” college tuition accounts - for the future care of family members with disabilities.

Rep. Crenshaw told a group of representatives from 35 different state Down Syndrome Associations gathered in front of the Capitol today that the introduction of the ABLE Act of 2009 was the “first step in helping Americans with disabled family members to invest in their future and help ensure that resources are available to prepare them to be financially, vocationally and mentally independent in adulthood.”

“This bill was inspired by the parents of a child with Down syndrome who brought the need for these special accounts to my attention. They, like all American parents, had one goal in mind - to help provide for the future of their child. Existing savings tools simply do not address these special needs.”

The ABLE Act of 2009 creates a tax exempt “ABLE Account” that could be used for expenses related to a disabled beneficiary including: education, medical and dental care, community based support services, employment training and support, moving, and assistive technology.

“Too often persons with disabilities are caught in between the cracks in our society. The ABLE Act will provide families with a savings tool that is flexible and portable. The accounts are designed to help ease difficult financial situations and provide peace of mind to the families of individuals with disabilities,” said Crenshaw.

Anyone may contribute to an ABLE Account and rollovers from other accounts would be allowed without penalty; however, contributions to these accounts are capped at \$500,000. Under the proposal, the principle in the account would accrue interest tax free during the life of the beneficiary.

When distributions are made to the beneficiary for qualified expenses, the distributions are excludable from the gross income of the beneficiary.

Crenshaw told the group that “it was time to roll up our sleeves and get to work advocating for the bill.” After leaving the group, Crenshaw introduced the legislation on the House floor.

Congressmen Patrick Kennedy (D-RI), Cathy McMorris Rodgers (R-WA), and Kendrick Meek (D-FL) joined Crenshaw as original cosponsors of The ABLE Act of 2009. Additionally, Senators Robert Casey (D-PA), Christopher Dodd (D-CT) and Orin Hatch (R-UT), introduced a companion bill in the U.S. Senate.

“Parents of children with disabilities face struggles on a daily basis that we can’t even begin to imagine,” said Senator Casey. “This legislation will help make it easier for those families to save for their care and for their future. It will provide families with the financial piece of mind they need.”

**ACTION NEEDED:** contact your congressional representatives to ask them to sign on as co-sponsors of this bill. Indiana residents, go to <http://tinyurl.com/d88vuy> to find contact information for your representatives. Michigan residents, go to <http://tinyurl.com/cqv688> (when you get to the sites, a list of representatives will come up. Click on the name, and you will be taken to a page with a letter that you can customize to send to your representative. It is very easy to use and only takes a few minutes.

I went to DC to a DS leadership conference in February. At that time, leaders from DS groups across the nation (and 6 groups from Indiana) went to Capitol Hill to talk to our representatives about this legislation. Representatives from Senators Bayh and Lugar’s offices appeared to be interested, but neither Senator Bayh nor Lugar has signed on as a sponsor yet. Neither has Congressman Donnelly. If the bill does not get enough sponsors, it will die in committee. So please take a few minutes to contact your representative. **THIS IS NOT JUST A DS ISSUE**-this will help anyone who has a disability...anyone can call-please pass this message on to anyone who can help get the word out...church, school, neighbors, family etc. Thank you. Kathy Ratkiewicz

## 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.

**Where's Chimpy? (Hardback)** By Berniece Rabe. It's bedtime, but Misty can't go to sleep - her toy monkey is missing! Misty has Down syndrome, but that doesn't mean she acts differently from any other child. As she and Daddy retrace all the places she went during the day, they seem to find everything but Chimpy, until...

## Fundraiser

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](http://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](mailto: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 also be at the next Family Support Night on May 15<sup>th</sup> for the talent show if you would like to view and smell the products. Thank you, Robin Wolford



## Pictures needed for 2010 calendar

We're gearing up to put together the 2010 calendar, and we need your pictures! Remember, the sooner you get them in, the better. This is a huge project, and hopefully we can get everything in line this year so we won't be pulling all nighters to meet the deadline. Clearly the pictures have to meet a set of guidelines in order to work for the calendar, but, as always, everybody who submits a picture that meets the guidelines will be included on the calendar.

### **The guidelines are:**

The bigger the better: obviously these pictures need to be high quality in order to come out nicely at 300dpi. Most digital camera pictures will work fine, but cell phone camera pictures are not large enough, and cannot be accepted.

Color pictures: The pictures do have to fit within the calendar theme, and black and white is -much- harder to match. If it all possible, color is preferred.

If you want your child on a particular month, (For example, their birth month.) please send a picture that would fit a possible theme for that month, or fits the general season. It's hard to put a snowy picture in July. Siblings are welcome to be included in the calendar, but must be in the same photo.

Film pictures will work too, if you can't scan them in...Send them to us, we'll return them to you after the calendar is finished. Paper printouts of pictures rarely work unless they're printed on high quality picture paper.

**Please send photos no  
later than July 31<sup>st</sup>, 2009.**

Mail photos to;  
Nathan Ratkiewicz  
26089 State Road 2  
South Bend IN 46619



Email to: [Kathy\\_R@comcast.net](mailto:Kathy_R@comcast.net)

## Family Support Night Talent Show



**Friday May 15<sup>th</sup>**

**5:30pm**

**Logan Center**

All kids and adults' with Down syndrome and their siblings are invited to take part in a Talent Show! Read a story, recite a poem, sing, show off your art work, do karate moves, play the piano, dance, jump rope, etc... the babies can even show off their sign language. This is a celebration of all our talented kids and adults.

We will start at 5:30pm with a quick meal followed by the talent show.

If you would like to have you child or family member participate in the show please RSVP as soon as possible to Kathy Ratkiewicz at 574-234-0590 or Shelly Schultz at 574-674-6769. We also need RSVP so we know how much food to order.

## Family Support Night Meet and Greet New Families



**Friday June 19<sup>th</sup>**

**5:30 pm Dinner and Fun**

**Logan Center**

**We need all families to come out to this important dinner to meet all the new families that have joined our group this past year. This is a great way to show support to these new families that are going through what we have once been through. Please RSVP to Kathy at 574-234-0590 or Shelly at 574-674-6769. Hope to see a big turn out!**

## Current Events

### May

- Tuesday 12<sup>th</sup> Mom's Night Out, 6:30pm at Applebee's on Lincolnway near Bittersweet
- Friday 15<sup>th</sup> Family Support Night 5:30pm at Logan Center Talent Show/refer to ad for more info.

### June

- Tuesday 9<sup>th</sup> Mom's Night Out, 6:30pm at Moe's Southwest Grill
- Friday 19<sup>th</sup> Family Support Night 5:30pm at Logan Center New Family Dinner to welcome & meet and greet all new and old families into the group

### July

- Tuesday 14<sup>th</sup> Mom's Night Out 6:30pm at Panera Bread on Ireland

### August

- Tuesday 11<sup>th</sup> Mom's Night Out 6:30pm Culvers on Main

### September

- Tuesday 8<sup>th</sup> Mom's Night Out 6:30pm at Hacienda on Portage
- Saturday 26<sup>th</sup> Michiana Down Syndrome Walk (Buddy Walk) more information to follow

### October

- Tuesday 13<sup>th</sup> Mom's Night Out 6:30pm at Famous Dave's on Grape Rd

### November

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

### December

- Tuesday 8<sup>th</sup> Mom's Night Out 6:30pm at Papa Vinos

## Notre Dame Club

We hope to have a new opportunity for our families to take part in next school year. We are very excited to share that we have been contacted by a group of Notre Dame Students who would love to start a program working with our children and young adults with Down syndrome. We met with them to discuss what kind of activities they would like to do and some of the ideas are going to movies, social club, playing games at your home and so on. It's a buddy system that is to help with social skills and they are even thinking of working on other skills like reading and math as long as it is in a relaxed fun way. It will take time to get everything worked out, so watch for updates in future newsletters.

## Special Spotlight News

Matthew Speheger had a big milestone that we want to share; he got on the bus all by himself... This was huge, just turned around and looked at his mom and pointed for her to stay put and off he went! We have a couple really proud parents and the DSFSAG would like to say way to go Matthew!

If you enjoyed our little spotlight news then we encourage you to share some of your big moments or just a silly story to put in our next newsletter. This is a wonderful way to celebrate our loved ones. Please send any story to [artrevell@aol.com](mailto:artrevell@aol.com) or to DSFSAG/Spotlight 51201 Old Cottage Dr, Granger, IN 46530.

We can't wait to read some amazing stories!



## Birthday Greetings

The DSFSAG are 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](mailto: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.

## Student seeking therapeutic work with child with disabilities

January – May 2010. Hours and pay flexible.  
Experience: Health and Counseling Aid at Friendship Ventures, a camp for people with special needs, LOGAN Social Skills Class volunteer and current ABA Therapy Autism Practicum. Optional free therapy through a practicum from August –December 2009, supervised by Kristin Wier. Contact Andrew Kerr at [akerr@nd.edu](mailto:akerr@nd.edu) or (412) 855-3087 for further details.

## Prenatal Awareness Initiative

We are forming a committee to work on getting accurate, up to date information about Down syndrome into the community and especially into the hands of area OB docs, geneticists, family docs, etc.

If anyone is interested in helping with this, please contact Kathy Ratkiewicz

(574) 234 0590 [Kathy\\_R@comcast.net](mailto:Kathy_R@comcast.net)

## 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).



## Logo Contest

Seeking talented designers to create a new logo for our group, as much as we love our current logo, it doesn't shrink well to put on letterhead. Furthermore, the current logo is designed with 3 colors and it loses its appeal when printed in one color only.

We are looking for a design that will look good either in multiple colors or a single color. The logo should be simple and not too busy using one or two colors preferred. If your logo design is chosen you will **win \$75**. Submit your logo design to [Artrevell@aol.com](mailto:Artrevell@aol.com) or DSFSAG/Logo 51201 Old Cottage Dr, Granger, IN, 46530 **by June 30, 2009**.

DSFSAG  
51201 Old Cottage Dr  
Granger, IN 46530

BULK RATE  
US POSTAGE  
PAID  
PERMIT NO.  
00000

