

# Down Syndrome Family Support and Advocacy Group Newsletter

February 2011



## WELCOME TO HOLLAND

By: Emily Perl Kingsley.

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will

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## We Have a Place to Call our Own The Michiana Down Syndrome Resource Center



Our group has a new home at 2444 Miracle Lane, Mishawaka 46545 in the Town & Country Shopping Center. We are very excited about this new adventure and hope that this will help us provide and expand our services to the Michiana Down Syndrome community. We will have our Lending Library at this new location. It will be open on Tuesdays and Thursdays from 12:00pm to 3:00pm and by appointment for other times. (Anne - 574-243-3808) We will expand these times as we get settled into our new space and will post the new office hours on our website and send out an announcement via the listserv.

Other services we hope to offer at this office will be:

- Dads' Meetings
- Family Support Meetings
- A Place to Meet New Families

Future possibilities:

- Small Classes: Reading, Yoga & Dance
- Teen Get Togethers

I'm sure we will have a lot of other ideas as we settle in. We can't wait to see you all there!

Free

**Saturday**  
**March 5, 2011**

9:00 am to 1:00 pm

**IUSB Main Cafeteria**  
**(The Grille)**

Administration Building  
1700 Mishawaka Ave  
South Bend, IN

Information and resources  
for individuals with  
disabilities, their families  
and the professionals who  
work with them.

Coordinated by:

**The Down Syndrome Family  
Support and Advocacy Group**

[www.michianadownsyndrome.org](http://www.michianadownsyndrome.org)

574-234-0590

In Partnership with:

**The South Bend Community  
School Corporation**

Sponsored by:

**The Master of Social Work  
Program at IUSB and  
Hosted By IUSB.**

**Directions:** To enter the Fair from Mishawaka Ave., turn south onto Esther Street and then left into the first parking lot. From the parking lot, enter the building between the Administration building and day care center. You can also follow Esther Street to Hildreth St., turn left and enter the visitor's lot. To enter the building walk around the old Associates Building and enter through the Administrative Building/Grille door on Ruskin Street.

## Special Needs Resource and Transition Fair

### New This Year! 20 Minute Break Out Sessions

#### Room A

9:00 am Mosaic  
9:30 am Social Security  
10:00 am A Rosie Place  
10:30 am LOGAN Center  
11:00 am MDwise Medicaid 101  
11:30 am The ARC of Indiana  
12:00 pm Vocational Rehabilitation  
Services  
12:30 pm Camelot Care Center

#### Room B

9:00: am UsBorne Books  
9:30 am Chiara Home  
10:00 am Reins of Life  
10:30 am Globe Star LLC  
11:00 am Anthony Wayne Service  
11:30 am 4 C's Community Coordinated  
Child Care  
12:00 pm Challenger Little League  
12:30 pm Goodwill Industries

### Participating Organizations

- 4 C's Community Coordinated Child Care
- A Rosie Place
- ADEC
- Anthony Wayne Services
- ASK (About Special Kids)
- Bridges Worship from Clay UMC
- Camelot Care Center
- Challenger Little League
- Chiara Home
- Children's Dispensary
- Children's Special Health Care Services
- Down Syndrome Family Support and Advocacy Group, Inc
- Family Voices Indiana
- Foundation for Music and Healing
- Friends of Christ from Northwest UMC
- GlobeStar LLC
- Goodwill Industries of Michiana
- Help at Home, Inc.
- InForming Life
- IN\*SOURCE
- Joint Services for Special Education School City of Mishawaka/Penn Harris Madison School Corp.
- LOGAN Center
- Madison Center
- MDwise
- Memorial Children's Therapy Center
- Memorial Hospital Driver Rehabilitation Services
- Mended Little Hearts
- Midwest Assistance Dogs
- Mosaic
- NAMI (National Alliance on Mental Illness)
- Oaklawn Psychiatric Center, Inc.
- Pinnacle Behavior Services
- REAL Services
- Reins of Life
- SBCSC INTERN Program
- Social Security
- SOLO (Special Outdoor Leisure Opportunities)
- Special Olympics of St. Joseph County
- Star Line
- St. Joseph County Public Library Literacy & Outreach Services
- St. Joseph Regional Medical Center Pediatric Therapy
- Sunshine Disability Ministries of Evangel Heights
- The ARC of Indiana
- TRANSP0 ACCESS
- UsBorne Books
- Vernon Manor Children's Home
- Vocational Rehabilitation Services
- Wheelchair Help.org
- WorkOne

## Exciting News In Research!

### TELL 15 FRIENDS Help Spread the Word.



The Down Syndrome Research and Treatment Foundation is dedicated to finding a treatment to improve cognition including learning, memory and speech for individuals with Down syndrome. Since their founding in 2004 they have become the leading private source of funding in the United States for Down syndrome cognition research.

The DSRTF needs our help by spread the word about the **plus15** campaign.

#### **What is plus15?**

**plus15** is an exciting new campaign to improve learning, memory, and speech for people with Down Syndrome.

**plus15** will make it possible for people with Down syndrome to live more independent lives.

Please share the **plus 15** campaign with 15 of your co-workers, family or friends. Please go to [www.dsrtf.org](http://www.dsrtf.org) to find out how.

Here is a snippet from the DSRTF's research page, please visit their website for more exciting news about all the research that is being done.

#### **Five Potential Drug Targets**

The results from the Discovery research phase are the most significant. Before DSRTF's founding there were no brain mechanisms identified to be associated with cognitive impairment in Down syndrome. By funding work at [Stanford University](#) and [Johns Hopkins University](#) DSRTF helped to identify **five new potential drug targets.**

During a webinar that Kathy Ratkiewicz listened to about the **plus 15** campaign Dr. Mobley and Dr. Reed said they anticipate being able to start clinical trials for medicines for improving cognition for individuals with Down syndrome in the next 5-7 months. The first study will be for adults ages 18-30.

We also want to share that the DSFSAG has made a \$1000 donation to the **plus 15** campaign. The day we made our donation a private donor pledged to match each donation by 3 to 1, so our donation turned into \$4000 toward research.

### Welcome to Holland Continued

meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.



### Holy Half

We are excited to announce that our group has been chosen to be one of the charities to benefit from the Holy Half Marathon that will be held at Notre Dame on **Sunday, April 10, 2011.**

We need a lot of volunteers of all ages to help with water stations and cheering on the runners on race day. We also need help in spreading the word about the race, because runners get to vote who their money goes to, so it would help us if we could get runners signed up who would vote for us. We would also like to thank the runners by giving them a cookie or brownie after they finish the race. We would appreciate donations for this please. We have also been invited to sell bakery items to the crowd at the race so we will need donation for that as well. Homemade items would be fantastic, but store-bought items would also be appreciated.

The ND students who are organizing the race also happen to be the founders of the Downs Time Club at ND. They will be putting together bags for the runners on Saturday April 9<sup>th</sup>. They would love to have our group members with DS there to help assemble the bags. If you have someone who is interested in helping, please contact Kathy @ [\(574\)234-0590](tel:5742340590) or [Kathy\\_R@comcast.net](mailto:Kathy_R@comcast.net). Info about the Holy Half @: <http://nd.edu/~holyhalf>

## Come Join us for The Wearing O' the Green and Participate in the St.



### Patrick's Day Parade!

**Annual St. Patrick's Day Parade  
South Bend, Indiana**

**Saturday, March 12, 2011 @ 11:00 a.m.**

Come walk with us, you don't have to be Irish to have some parade fun! This is a great way to bring awareness to Down syndrome, and since **World Down Syndrome Day** is on March 21<sup>st</sup> we can make this a celebration of that too.

WDS Day was created to generate awareness of Down syndrome and to encourage acceptance in the community.

Everyone benefits when we celebrate diversity! If you would like to join in the fun, please email Colleen at [cmreck@comcast.com](mailto:cmreck@comcast.com) to register. We will keep you informed where we will meet before the parade.

#### Parade schedule:

10:30 a.m. all participants meet in the staging area. Please be on time!

11:00 a.m. the parade steps off.

Immediately following the parade (approximately 12:00 noon) will be the greening of the East Race at Seitz Park.

\*\*\*Note: the parade has never been cancelled, come rain, snow or shine. It will only be cancelled in the case of severe weather. Make sure you dress appropriately!

#### Parade Route:

The parade will begin promptly at 11:00 a.m. and will start at the corner of Jefferson and Francis streets.

- The route will travel west on Jefferson St.
- It will turn north on Niles Avenue
- Ending at Washington Street, near Seitz Park.
- Please continue in the parade through to the end. Do not leave the parade before you get to Washington Street.
- The greening of the St. Joseph River will immediately follow at Seitz Park.

\*\*\*Note: The parade will be about 7 or 8 blocks long, plus a similar length for set up. Please wear appropriate clothing and footwear if you are walking. Little ones can be pulled in wagons, decorated for the parade if you wish. \*\*\*

## One Day Basket Ball Camp February 27, 2011

The Notre Dame Hockey players would like to invite any child from our group who would like to participate on a one day basketball camp at the Roc at Notre Dame. It will be from 1:30 to 3:30 on February 27<sup>th</sup>. Please RSVP no later than February 20<sup>th</sup> to Cheryl Speheger @ [cspeheger@yahoo.com](mailto:cspeheger@yahoo.com) or 574-277-6343.



## Recreational Opportunities

The DSFSAG offers Recreational Scholarship money to the following four organizations (*Reins of Life, Foundation for Music & Healing, The Children's Dispensary, and Kindermusik*) on behalf of our members with Down syndrome. These organizations will give our members with Down syndrome a discount on their enrollment fees. The amount of the discount varies depending on the number of members who participate.

#### ► Reins of Life, Inc.

Therapeutic horseback riding program offers children from ages 2 on up the opportunity to learn how to take care of and ride a horse. Sessions range between 6 and 8 weeks. Website: [www.reinsoflife.org](http://www.reinsoflife.org)

#### ► Foundation for Music and Healing

Individual music instruction for students of all ages with disabilities or special needs.  
Website: [www.nd.edu/~spower/musichealing/index.html](http://www.nd.edu/~spower/musichealing/index.html)

#### ► The Children's Dispensary

The Children's Dispensary provides social and recreation programs to enhance the learning and enrich the lives of people with special needs ages 5-18 years. Their programs include Fun and Learn, Bowling and Teen Club. Website: [www.childrensdispensary.org](http://www.childrensdispensary.org)

#### ► Kindermusik® with Amy Reinert, LLC

"Kindermusik is a classroom learning experience. We teach children music so they can become better learners. It's not about making little Mozart's. It's about developing skills in the whole child - age's newborn to 7 years - cognitive, physical, social, emotional, language and musical. For more than 25 years, we have believed music is the best conductor for learning."

Website: <http://kindermusikwithamy.kindermusik.net/>

## 2011 Current Events



February 27 – Basket Ball Camp with ND Hockey Players, @ ND's The Roc

March 5 – Resource Fair IUSB

March 12 – St. Patrick's Day Parade, South Bend

March 21 – World Down Syndrome Day

March 26 – Kim Voss Conference, John Young Middle School

March 8 – MNO @ Penn Station Subs, South Bend Ave

April 10 – Holy Half Marathon, Notre Dame

April 12 – MNO @ Wings Etc, Grape Road

May 10 – MNO @ Hacienda, Portage

June 14 – MNO @ Famous Dave's, Grape Road

July 12 – MNO @ Louvered Door, Western Ave

August 9 – MNO @ Moe's, University Drive

September 13 – MNO @ TGI Friday's, Erskine Plaza

### **October 1 - Michiana Down Syndrome Walk**

October 11 – MNO @ Outback Steakhouse, Grape Road

November 8 – MNO @ Applebee's, Erskine Plaza

December 13 – MNO @ Carrabba's, Day Road

We will post these and other dates as we plan future events on our website at

[www.michianadownsyndrome.org](http://www.michianadownsyndrome.org)

\*MNO = Moms' Night Out



## Lending Library

Our Lending Library is now located in our New Office space at 2444 Miracle Lane, Mishawaka (Town & Country Shopping Center) The Library will be open on Tuesdays and Thursdays from 12:00pm to 3:00pm and by appointment @ 574-243-3808.

### Feature Books:



#### **From Grief to Celebration, How One Family Learned to Embrace the Gift of Down Syndrome**

The story of how one family learned to embrace the unexpected birth of a daughter with Down syndrome. From the grief associated with an unexpected event to the celebration of life their daughter has taught them and brings to them every day. This book describes the ten stages the family went through, including grief, research, incorporation, inclusion, and finally planning in their journey to celebrating the magic of Down syndrome.



#### **The Down Syndrome Transition Handbook: Charting Your Child's Course to Adulthood**

This handbook outlines the steps of transitioning, with an emphasis on the necessity of the child playing an active role in the process. It considers everything families need to know--from meeting broad, basic needs such as finding meaningful ways to fill one's days (work, volunteering, leisure activities, training & education, exercise) and how to get around (driving vs. using public transportation) to addressing specific needs such as whether to leave high school at age 21 or earlier and how to maintain eligibility for benefits by keeping income and assets within allowable limits.



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**Benefits:**

- No headcount
- Pay only for [unclear]

## Birthday Greetings

The DSFSAG would like to send everyone with Down syndrome a birthday greeting but in order to do this we need everyone's birthday date. If your family member with Down syndrome is not receiving a birthday greeting from us or if you're not sure if we have the birthday date and 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)



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Each Office Independently Owned and Operated

## 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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