

# Down Syndrome Family Support and Advocacy Group Newsletter

DATE



## Down Syndrome is Contagious

By Wendy Holden.

Down syndrome is a genetic disorder characterized by a triplication of the genetic material on the 21st chromosome. This trisomy occurs with the first division of the developing zygote, as a result there is extra genetic material present in every cell of the individual. Recently, science has discovered that this cellular abnormality is highly contagious. As result, family members (and even friends) of individuals with Down syndrome often find themselves exhibiting dramatic changes due to this "something extra" permeating their bodies at the cellular level. These changes manifest themselves in a number of ways.

Something extra in the visual cortex results in parents who view the world differently. In addition to seeing things in an entirely new light, these parents also report having an increased ability to focus on what is important. Spontaneous appearance of tears of joy has also been confirmed. The section of the brain used in logical thought undergoes dramatic changes. Parents suddenly find themselves able to comprehend and discuss complex medical procedures. The ability to decipher long strings of acronyms appears almost immediately and it is not uncommon for affected parents of newborns to be able to differentiate between ASD, VSD and PDA. Familiarity with G-tubes, Pic lines and the NICU is another side effect.

Over time, the entire nervous system is transformed, enabling parents to perform tasks previously thought impossible. These changes result in individuals finding the nerve to advocate before

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## Talent Show



When: Friday, May 4, 2012  
Where: Little Flower Church  
(54191 Ironwood Rd., South Bend, IN 46635)

Time: 6:00pm to 9:00pm

Dinner will start at 6:30 we will provide main dish, table ware and drinks. **Please bring a side dish or dessert to share.**

All kids and adults' with Down syndrome (siblings may perform together) 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 kids' talents. If you would like to have you child or family member participate in the show please RSVP as soon as possible to Kathy at 574-234-0590 or Anne 574-243-3808. We also need RSVP so we know how much food to order

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# A Night of Art & Blues



## **Inaugural Cocktail Reception & Silent Auction**

Friday, May 11, 2012  
7pm at O'Briens Pub  
In the Compton Family Ice Arena  
on the campus of  
the University of Notre Dame.

**Register On-line at:**  
[www.researchds.org](http://www.researchds.org)

### **RDS GOALS:**

- Develop safe and effective therapies to assist memory, learning and communication
- Enhance awareness of Down syndrome cognitive research
- Expand and enhance life opportunities, both educational and occupational, of people with Down Syndrome
- Address increased frequency and earlier onset of cognitive decline
- Fund scientific research that is directed towards understanding origins of intellectual difficulties

Come and have fun! Tickets are \$75 (\$125 for two). It is going to be a great night with an open bar, lots of great food, live blues music, and a festive silent auction. We would love to have you be there to support us and have a great time. Our primary feature for the silent auction will be original art created by people with special needs. However, we also have a large number of other interesting items (e.g. a getaway on Lake Michigan that sleeps 22, a private chef's dinner, Keurig brewers, and many more) to bid on as well.

**Why Are We Doing This?** Like all of you, our lives have been forever made better by Down

syndrome. Our daughters, sons, sisters, friends, and neighbors with Down syndrome have made our lives more enriching and we want to help give them every opportunity we can. Wonderfully, we have been blown away to learn that over the last 5 years some amazing things have been happening with Down syndrome cognitive research. Essentially, up until 10 years ago, there was never any research on the cognitive effects of Down syndrome because scientists thought that it was an intractably complex problem (too many gene mutations to solve). A combination of advances in the mapping of the human genome, advances in understanding of neuroplasticity in the brain, and the development of a mouse model for Down syndrome testing have changed all of that and now some of the top neuroscientists in the world are working furiously on new treatments at Stanford, Johns Hopkins, UC-San Diego, and a few other places. This work has now been published in *Science* and other top-of-the-field leading journals, with 2007 considered a 'miracle year' for discoveries in this space. The possibility of substantially improving learning, memory, and situational awareness for people with Down syndrome is now being viewed as a real and near term possibility. The word 'revolutionary' gets thrown around a lot, but in this case the possibilities seem to be pretty ground breaking.

A limitation for this research is that because there has historically been little perceived opportunity, there has never been much funding going into this work. With the breakthroughs, this is starting to change. To help get things moving a few of us with Notre Dame connections have organized a group at Notre Dame to plan a major fundraiser on campus. In fact, in addition to the help of the Down syndrome parents and community, our group of supporters now numbers over 75 faculty, staff, administrators, alumni, and students from around the University, many of whom have been working for the last few months on planning this major event at the ice arena to raise money for this great work.

large crowds, speak to classrooms of medical students and educate the population at large about issues they are passionate about. These changes are closely tied into dysfunctions in the verbal abilities, which makes it virtually impossible for parents to bite their tongue. Often, individuals who previously considered themselves reserved will find themselves outspoken and effective communicators.

The pulmonary system is altered to a dramatic extent, parents report having their breath taken away at the slightest prompting. The cardiovascular system develops similar vulnerabilities and reports of hearts pounding loudly and swelling unexpectedly are not uncommon. One mother reported that her heart skipped a beat when her son smiled at her for the first time.

The extremities are also altered. Arms reach out to strangers for support, and in turn, hands comfort and nurture those in need. Legs strengthen and balance improves, allowing parents to stand firm in their convictions and walk without faltering, even when shouldering a heavy load.

Scientists are baffled by the widespread scope of these symptoms. Equally perplexing is the response of those afflicted. Parents readily acknowledge fundamental changes in their being, however, almost universally declare a preference for their new, altered level of functioning. "I wouldn't change a thing" is a common refrain. Apparently, the presence of a little "something extra" enhances the lives of individual fortunate enough to be infected.

## **Birth to 3yr Group**

All families with children ages birth to 3 yrs are welcome to come to our monthly meetings at the Michiana Down Syndrome Resource Center, 2444 Miracle Lane, Mishawaka, IN on the last Wed. of each month at 6:30. Children are welcome to attend as well. Parents can visit with each other while their kids play. The next meeting will be April 25th. Please see calendar of events for future dates. RSVP to Kathy 234-0590 Kathy\_R@comcast.net or Anne 243-3808 artrevell@aol.com (Oct. date changed due to Halloween and no meeting in Dec.)

## **World Down Syndrome Day Celebration at Notre Dame**

March 21<sup>st</sup> marked the 7th anniversary of **World Down Syndrome Day** and the **first** time this **day** was officially observed by the United Nations. To celebrate, the Teaching Exceptional Children Program of the Alliance for Catholic Education (ACE) and the Jacques Maritain Center sponsored a celebration at Notre Dame. Dr. Joyce Johnston and Dr. Jennifer Borek, both of ACE, planned and coordinated the event. The theme was "Made in God's Image". The celebration's highlight was a Mass in the Basilica of the Sacred Heart on Notre Dame's campus. The Mass was celebrated jointly by Fr. Bill Dailey, Fr. Peter Rocca, and Fr. Bill Miscamble, all members of the Congregation of Holy Cross. Fr. Dailey preached a moving homily, which began by pointing out the irony of a special day to raise awareness of the value of the lives of persons with Down syndrome, a fact which is so obvious to those who know someone with an extra 21<sup>st</sup> chromosome. Three members of the local Down syndrome community, Katie Henry, Veronica Go, and Eric Shultz, contributed to the liturgy as altar servers. The Basilica was full of students, faculty, and a large number of individuals with Down syndrome and their families.

Mass was followed by a reception in Remick Commons of Carole Sander Hall, the beautiful new building which is home to the ACE program. Pizza and other refreshments were served, as families visited with students and faculty. Several World Down Syndrome Day videos, one made by Down Syndrome International, and the other made by IDSC for Life, played on a large screen in the background. Those organizing the event, as well as many of the families participating, commented on the joyfulness of the evening's festivities, and were grateful for a chance to celebrate the gift of individuals with Down syndrome. Mark your calendars for next year, because Drs. Borek and Johnstone said that they would like to make this an annual event at Notre Dame!

## 4-7 Year Old Group

For our first meetings, we have had time to socialize and get to know each other. The kids have made crafts and we usually have lunch. Due to spring vacations, April's meeting will be on April 28<sup>th</sup> from 11 am to 12:30. We are meeting at the Michiana Down Syndrome Resource Center, 2444 Miracle Lane, Mishawaka (Town and Country Shopping Center) we will have an art project for the kids to do for the RDS fundraiser.

**There will not be a May meeting.**

Please RSVP to

Future dates will be decided by the group at the June meeting.

## 8-12 Year Old Group

Our next gathering will be Friday April 27<sup>th</sup> from 6 to 8 p.m. at the Michiana Down Syndrome Resource Center, 2444 Miracle Lane, Mishawaka. We will have volunteers from St. Mary's do activities with our kids while the parents are two doors down at Cosmo and Susie's for a parent support night.

Please RSVP if you would like to attend this month's gathering. Those who RSVP will receive \$5 towards their meal at Cosimo and Susie's... Pizza will be provided at the Center for the kids  
RSVP to Susan 299-3235 [stpearson@sbcglobal.net](mailto:stpearson@sbcglobal.net)  
For upcoming dates, see the calendar of events.

## DS Teen/Adult Night

Calling all teens and adults! Join us for a monthly fun-filled activity! We will meet on the 3rd Friday each month from 6pm to 9pm-locations will be announced each month. This month we will be at Strikes and Spares on April 20<sup>th</sup>, for upcoming dates, see the calendar of events:

Please RSVP to Anne 243-3808 [artrevell@aol.com](mailto:artrevell@aol.com)  
or Kathy 234-0590 [Kathy\\_R@comcast.net](mailto:Kathy_R@comcast.net)

## St Patrick's Day Parade



This was our 2nd annual participation in the St. Patrick's Day parade. The night before we had over 10 families at the center to decorate our float, it was a lot of fun trying to be creative, we hope to get better at it every year and maybe win the grand prize for best float in the near future.

The parade was a blast, we had around 10 families dressed in St. Patty's day spirit come out to walk and ride in our float. This is a wonderful opportunity for our group to let the community get to know us; **we hope to make this an annual event...** so mark your calendars for next year St. Patrick's Day so we can have even more families participate.

## Prenatal Testing

With the new and earlier prenatal tests that are now on the market, it is more important than ever that expectant parents receive accurate and unbiased information about Down syndrome. For more information, go to : [http://www.cbsnews.com/8301-505269\\_162-57382535/early-prenatal-test-raises-ethical-questions](http://www.cbsnews.com/8301-505269_162-57382535/early-prenatal-test-raises-ethical-questions) (or Google 'CBS news early prenatal testing')

Michiana Down Syndrome has a supply of the Canister booklets Delivering a Down Syndrome Diagnosis (for physicians) and Understanding a Down Syndrome Diagnosis (for expectant or new parents) The booklets were developed with input from the national Down syndrome organizations, American College of Medical Genetics, the American Congress of Obstetricians and Gynecologists and the National Society of Genetic Counselors. If you, your OB, or your child's doctor would like a free copy of these booklets, please contact [Kathy\\_R@comcast.net](mailto:Kathy_R@comcast.net) or (574) 234-0590

## Resource Fair

This year's Resource Fair was an amazing event. So many resources, so many volunteers nice to see so many people with the same goals all in one place! Over 65 agencies and organizations had information booths with a wide variety of resources. Can't wait until next year! Thanks to our volunteers and community partners- SBCSC and the Master of Social Work program at IUSB!

Cheryl Speheger.



## DS Group Family Directory

Information needed for updated Family directory if you would like to have your family included in the Michiana Down Syndrome Family directory, please send the following information to Rick Podrasky at [rpodrasky@gmail.com](mailto:rpodrasky@gmail.com) no later than June 1st:

Name and heads of household

Address (optional)

Home telephone /cell phone (optional)

email(s) (optional)

Child's name (plus age)

Sibling's names and ages

If email access is an issue, you may also call

574-243-3808 or mail the information to:

DS Directory DSFSAG, 51201 Old Cottage Dr,  
Granger, IN 46530

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 June 1, 2012. There isn't a specific theme other than celebrating the talent of those in our community, so the more entries - the merrier!

Thanks! Rick

## Calendar of Events

- April 25th - Birth to 3yrs Resource Center
- April 27th - 8-12yr Group Resource Center
- April 28th - 4-7yr Group Resource Center
- May 2nd - iPad Workshop at Logan 6:00 - 8:00pm for Parents
- May 3rd - iPad Workshop at Logan 9:00am-noon for Professionals
- May 4th - Talent Show 6-9pm Little Flower Church
- May 8th - MNO Between the Buns, SB Ave
- May 18th - Teen/Adult Night - Place TBA
- May 25th - 8-12yr Group - Place TBA
- May 30th - Birth to 3yr - DS Resource Center
- **June 9th - 4-7yr Group - Place TBA**
- June 12th - MNO Penn Station, SB Ave
- June 15th - Teen/Adult Night -Place TBA
- June 16th - Old 2 Gold 9am to noon
- June 27th - Birth to 3yr - DS Resource Center
- June 29th - 8-12yr Group - Place TBA
- July 10th - MNO Steak N Shake, Grape Rd
- July 20th - Teen/Adult Night -Place TBA
- July 25th - Birth to 3yr - DS Resource Center
- July 27th - 8-12yr Group - Place TBA
- August 14th - MNO TGIF, Ireland Rd
- August 17th - Teen/Adult Night -Place TBA
- August 29th - Birth to 3yr - DS Resource Center
- August 31st - 8-12yr Group - Place TBA
- September 11th - MNO Red Lobster, Main St
- September 21st - Teen/Adult Night -Place TBA
- September 26th - Birth to 3yr - DS Resource Center
- September 28th - 8-12yr Group - Place TBA
- October 9th - MNO Flat Top Grill, UP Mall
- October 19th - Teen/Adult Night -Place TBA
- October 24th - Birth to 3yr - DS Resource Center
- November 13th - MNO Cosimos & Susie's Town & Country Shopping Center
- November 16th - Teen/Adult Night -Place TBA
- November 28th - Birth to 3yr - DS Resource Center
- November 30th -8-12yr Group - Place TBA
- December 11th - MNO Papa Vino's Edison Lakes Parkway
- December 21st - Teen/Adult Night -Place TBA
- December 28th -8-12yr Group - Place TBA

MNO - Mom's Night Out

TBA - To Be Announced

## You Ought to Be in Pictures!

2013 Snap Shot Calendar Pictures Wanted!

We're gearing up to put together the 2013 Calendar, and as always, the more the merrier! Due to the massive demand, and the fact that we only have space for approximately 60 pictures, generally we use the first pictures received that meet the guidelines below. The deadline for all pictures is July 1st, but if you already have the picture you'd like to submit, early submissions will be greatly appreciated.

### Submission guidelines:

If you want your child on a particular month, (for example, their birth month,) please specify the month, and make sure the picture is season-appropriate. Remember that the calendar-page slots will fill up quickly, so if you want a calendar-page slot, the sooner you submit your picture, the better your chances.

While you are more than welcome to send in more than one picture, please specify which one you would most like to see showcased.

Pictures need to be color and in a digital format of 300dpi (dots per inch) or greater.

Please identify the individuals in the picture(s) by name, so we can credit them properly within the calendar.

Send digital pictures to [Kathy\\_R@comcast.net](mailto:Kathy_R@comcast.net)

Or Send your photo to:

Kathy Ratkiewicz  
26089 State Road 2  
South Bend, IN 46619



## DSRTF

The Down Syndrome Research and Treatment Foundation uses the funds raised for research  
To: Improve Learning, Memory and Speech  
To: Prevent the early onset of Alzheimer's  
To: Enable a Greater Independence  
On March 21, all donations to the DSRTF were matched 3:1 by some of their generous donors, so our group donated \$1000 and with the matching funds brought our donation up to \$4000 towards research!

For more information about all the research going on or to make a donation yourself please visit their website at: [www.dsrtf.org](http://www.dsrtf.org)

## Dr. Brian Skotko

On February 22nd and 23<sup>rd</sup>, Michiana Down Syndrome hosted a series of presentations by Dr Brian Skotko of Boston Children's Hospital. His presentations included **Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians** to Grand Rounds at Memorial Hospital, **and New Prenatal Tests for Down Syndrome: Everything You Need to Know and Should be Doing** to the Indiana University School of Medicine's Mini- Medicine School Series. These sessions covered the most current information on the new and upcoming prenatal tests. We were very excited for this opportunity to partner with Memorial Hospital for the medical presentations and the new relationships formed from his visit.

On the 23<sup>rd</sup>, Dr. Skotko gave a presentation on **Healthy Students with Down Syndrome: All the Medical Updates that Educators Need to Know** at Logan Center. The presentation at Logan Center was attended by over 40 therapists, educators and other professionals! It consisted of various different topics relating to how Down syndrome can and does affect the learning of individuals with Down syndrome. There will be links to more information on the presentations at [www.MichianaDownSyndrome.org](http://www.MichianaDownSyndrome.org).

## **Down Syndrome Affiliates In Action**

On February 29 - March 3 Kathy Ratkiewicz and Dru Neice attended the Down Syndrome Affiliates in Action Annual Leadership Conference in Washington, D.C. The conference was held in DC to coincide with The Buddy Walk on Washington (a devoted day of advocacy on Capitol Hill, coordinated by the National Down Syndrome Society). Down Syndrome Affiliates in Action (DSAIA) is a national trade association composed of nearly 80 Down syndrome support organizations from across the country. This is the sixth year for the conference, in which national experts and affiliate leaders shared research, successful programs and operations and development tools. During the advocacy day on Capitol Hill, Kathy & Dru were able to meet with representatives from Congressman Joe Donnelly and Marlin Stutzman's offices, to try and gain support on The Able Act, Increasing NIH Research Funding and ESEA Reauthorization. The purpose of DSAIA is to serve Down syndrome affiliates through collaboration, resource sharing, and networking, DSFSAG has been involved with DSAIA since its inception in 2006.

## **iPad workshop at Logan May 2nd & 3rd**

LOGAN and Michiana Down Syndrome will present "iPad: A tool for persons with disabilities" workshop on Wednesday, May 2 (for parents 6-8pm) and Thursday, May 3 (for professionals) at LOGAN Center. The workshop will train families and professionals in the many practical and educational applications of the iPad for persons with disabilities. Lead by IRCA Educational Consultant Kristie Lofland, MS, CCC-A, the sessions will teach parents and professionals how to integrate technology, use the best apps, and discover what works for your family. Download a workshop brochure at [www.logancenter.org](http://www.logancenter.org) with complete information and registration cost.

## **Able Act**

The Achieving a Better Life Experience Act (ABLE) of 2011 (S. 1872/H.R. 3423) was introduced on Nov. 15th in the 112th Congress (2011-2012 Congressional cycle). The bill is being led by a bipartisan, bicameral set of Congressional champions, including Senator Robert Casey, Jr., (D-PA), Senator Richard Burr (R-NC), Congressman Ander Crenshaw (R-FL), Congressman Chris Van Hollen (D-MD), and Congresswoman Cathy McMorris Rodgers (R-WA).

The ABLE Act will give individuals with disabilities and their families the ability to save for their child's future just like every other American family, and help people with disabilities live full, productive lives in their communities without losing benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary's employment, and other sources. The account could fund a variety of essential expenses for individuals, including medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation.

The ABLE Act provides individuals with disabilities the same types of flexible savings tools that all other Americans have through college savings accounts, health savings accounts, and individual retirement accounts. The legislation also contains Medicaid fraud protection against abuse and a Medicaid pay-back provision when the beneficiary passes away. It will eliminate barriers to work and saving by preventing dollars saved through ABLE accounts from counting against an individual's eligibility for any federal benefits program. We currently have 6 cosponsors in the Senate and 40 in the House. If your Member hasn't signed on, please take a few moments and email your Rep and two Senators by visiting the following website for a link:

<http://www.ndss.org/en/Policy/Legislation-and-Initiatives>

## **St Joseph/Benton Harbor** **Mom's Night Out**

We are very happy to announce a Mom's Night out in the St Joseph/Benton Harbor and surrounding areas. This is a great opportunity to develop friendships and exchange experiences and resources.

The Goal is to meet on the third Monday of every month & move into children and family events as possible.

Please contact Bonnie at 269-556-0401 to RSVP or for more information.

### **Just Like You Video link at:**

[http://www.youtube.com/watch?v=\\_EaWBdcbwZw](http://www.youtube.com/watch?v=_EaWBdcbwZw)

### **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).

DSFSAG  
51201 Old Cottage Dr.  
Granger, IN 46530



