



**Down Syndrome**

**Indiana™**



Volume 7 Issue 2

*Dedicated to enhancing the lives of individuals with Down syndrome...*

**common bonds**

Spring 2009

## Down Syndrome Advocates from Across the US Visit Capitol Hill

By Tom Milvert

Down syndrome organizations from across North America converged on Washington DC in late February to bring a message of unity and support for public policy important to people with Down syndrome. Leaders from over 86 Down syndrome advocacy and family support organizations joined forces with self advocates as they visited Capitol Hill as part of the Down Syndrome Affiliates in Action Legislative Advocacy Day.

Indiana was very well represented as Down syndrome organizations from across participated in meetings with our elected officials:

- Down Syndrome Indiana
- Dads Appreciating Down Syndrome
- S.M.I.L.E. on Down Syndrome
- Down Syndrome Family Support Assoc. of Southern In, Inc
- Down Syndrome Family Support and Advocacy Group of Michiana
- Columbus Area Down Syndrome Support Group

The day started with a Congressional Down Syndrome Caucus breakfast reception. Congresswoman Cathy McMorris-Rodgers, whose son Cole has Down syndrome, was joined by Congressman Patrick Kennedy in welcoming the Affiliates in Action to Capitol Hill. In their brief remarks, they spoke passionately about the importance of public policies that can significantly enhance the quality of life for individuals with Down syndrome. Under their leadership, the newly formed Congressional Down Syndrome Caucus is off to a great start in promoting public policy on behalf of the 400,000 Americans with Down syndrome.

You could feel the excitement among the nearly 300 Down Syndrome Affiliates in Action participants, gathered on the steps of the United States Capitol, when Congressman Andre Crenshaw walked down to announce that he had just introduced the Achieving a Better Life Experience Act (ABLE Act). The ABLE Act, will provide individuals with disabilities and their families the opportunity to create a tax deferred disability savings account that could fund a variety of essential expenses, including medical care, education, employment training, assistive technology as well as housing and transportation.

The Indiana delegation joined forces for visits to Senator Evan Bayh's and Senator Richard Lugar's offices. The group presented a powerful message in support of the Achieving a Better Life Experience Act (ABLE Act) and appropriations to fund the Kennedy Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act. Indiana can be very proud of our self-advocates, Jessica Green and Mark Hublar, who spoke on our behalf. Their message was straight from the heart and had a bigger impact in our meetings than anything else that was said!

In the afternoon, the Indiana delegation visited their individual representatives offices. Visits were completed to the following offices:

- Congressman Dan Burton
- Congressman Andre Carson
- Congressman Joe Donnelly
- Congressman Baron Hill
- Congressman Brad Ellsworth

### A Call to Action

While the Down Syndrome Affiliates in Action Legislative Action Day was very successful, it is only the beginning and much work lies ahead. The Indiana delegation is excited about moving forward as a Governmental Affairs Committee and will be working to strengthen relationships across the state and establish a strong grassroots base of support and action for public policy. Watch for details as we move forward. If you are interested in being involved, please contact Tom Milvert at [t.j.milvert@sbcglobal.net](mailto:t.j.milvert@sbcglobal.net)

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*Down Syndrome Indiana is dedicated to enhancing the lives of individuals with Down syndrome. Our mission is to serve as a conduit of information, support and advocacy for individuals with Down syndrome and their families, which promotes growth and inclusion in the community.*

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### Statement of Policy and Disclaimer:

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### Reprints from common bonds:

We invite others to reprint items from common bonds. We ask that you provide proper credit, listing the source, as well as notify us. Please note that you must contact the original source for permission to use articles that we have reprinted.

### About :

Down Syndrome Indiana is a not-for-profit organization serving the needs of individuals with Down syndrome and their families. DSI is supported by a dedicated board of directors, staff and countless volunteers. The programs and services provided by Down Syndrome Indiana are supported totally by individual and corporate donations combined with annual fund raisers and special events.

### Vision Statement:

Down Syndrome Indiana is committed to supporting individuals with Down syndrome throughout their lifetime by: promoting self advocacy, inclusion and participation in the community, being the most comprehensive resource on Down syndrome, serving as the state leader for public policy advocacy, and increasing positive public awareness .

### Board of Directors:

Steve Simpson –President  
Dr. Richard Schreiner –Vice President  
Ann Gibson –Secretary  
Rob Morgan –Treasurer  
Ta-Tanisha Crumble  
Vicki Dayan  
Ali Dillingham  
Angie Everton  
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Jeff Huffman  
Tom Milvert  
Sherri O’Keefe  
Ted Scofield  
Gale Spells Bellamy  
Roscoe Scott  
Brad Wilt

And your help is needed in moving the ABLÉ Act forward and to secure appropriations for the Kennedy Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act. Please consider contacting your elected officials in Washington D.C. and ask for their support. A brief script is provided that will make this easy.

### If contacting a House Member:

I am <insert full name> from <insert city in Indiana>. I am calling to encourage <insert your congressman’s name> to cosponsor House Bill H.R. 1205 – The Achieving a Better Life Experience Act or ABLÉ act. This bill will help me and my <insert son, daughter, niece, grandchild, friend, etc> plan for a secure future and provide the flexibility to accommodate the uncertainty and wider range of expenses that can result from living with a disability. I would also like to encourage <insert your congressman’s name> to support appropriations in fiscal year 2010 for implementation of the Kennedy-Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act. This will ensure that families who receive a diagnosis of Down syndrome will be offered up-to-date and accurate information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options.

### If contacting a Senate Member:

I am <insert full name> from <insert city in Indiana>. I am calling to encourage <insert your congressman’s name> to cosponsor Senate Bill S. 493 – The Achieving a Better Life Experience Act or ABLÉ act. This bill will help me and my <insert son, daughter, niece, grandchild, friend, etc> plan for a secure future and provide the flexibility to accommodate the uncertainty and wider range of expenses that can result from living with a disability. I would also like to encourage <insert your congressman’s name> to support appropriations in fiscal year 2010 for implementation of the Kennedy-Brownback Prenatally and Postnatally Diagnosed Conditions Awareness Act. This will ensure that families who receive a diagnosis of Down syndrome will be offered up-to-date and accurate information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options.

### Stimulus Package

There is significant funding in the recently passed stimulus package targeted towards individuals with disabilities. The Down syndrome community needs to ensure that this money is working for individuals with Down syndrome and their families.

Medicaid Funds – States will be receiving significant funds to support the Medicaid programs. The disability community needs to target these funds for Home and Community Based Services to help move people in Indiana off the Medicaid waiver waiting list.

IDEA Funds - Approximately \$12 billion will be allocated to the states. There is a provision in IDEA 2004 that gives discretion to local schools spend up to fifty percent of any increase in special education funds over the previous year on spending unrelated to providing direct services to students with disabilities. Families should contact their local school boards to advocate for allocating these funds fully to special education services.

Technology Funds for Schools – Approximately \$13 billion will be allocated to the states. At this point it is uncertain how this money will be directed to schools, but it is important that significant funding is targeted towards assistive and adaptive technologies that improve educational outcomes for students receiving special education services.

Down Syndrome Advocates Lobby on Capitol Hill

Patricia E Bauer blogged about this event. Her post can be located at: <http://www.patriciaebauer.com/2009/03/04/down-syndrome-capitol-hill/>

Comprehensive contact information for our Senators and Representatives is available on page on page 11.

## DADS APPRECIATING DOWN SYNDROME

Join us for the 7th Annual D.A.D.S. golf outing. In just a few short years, the D.A.D.S. golf outing has become one of the largest outings in the midwest, raising nearly \$400,000 for D.A.D.S. and Down Syndrome Indiana, and offering our sponsors exposure to our annual field of over 300 golfers.

D.A.D.S. is an organization of fathers dedicated to enhancing the lives of their children who happen to have Down syndrome. D.A.D.S. was started in Indianapolis in 2002 and now boasts over 500 members and 30 chapters in the US, Canada, the UK and Australia. Our mission is simple:

*To assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome.*

Please visit our website at [www.dadsnational.org](http://www.dadsnational.org)

Contact **Bill Smith** at:  
[dadsgolf@gmail.com](mailto:dadsgolf@gmail.com)  
or (317) 445-0885



D.A.D.S. is proud to be a part of Down Syndrome Indiana (DSI).

DSI is a not-for-profit 501(c)3 organization; therefore your donation may be tax deductible.

Federal Tax ID#: **35-1957015**



## THE 7TH ANNUAL D.A.D.S. GOLF OUTING OFFICIAL REGISTRATION FORM

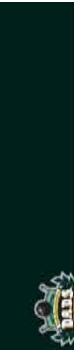


Down Syndrome Indiana  
Dads Appreciating Down Syndrome  
3050 N. Meridian St.  
Indianapolis, IN 46208  
317-925-7617  
888-989-9255



[www.downsyndromeindiana.org](http://www.downsyndromeindiana.org)  
[www.dadsnational.org](http://www.dadsnational.org)

**Friday, May 29, 2009**  
Pebble Brook Golf Course  
3110 Westfield (St Rd 32)  
Noblesville, Indiana 46062



# GOLFER REGISTRATION

### Schedule of the day's events:

- Registration & Lunch – 10:30-11:30am
- Pre-Golf Activities
- 18 Hole – Best Ball Scramble – 12:00pm
- Dinner and Raffle – 5:00pm

### Prizes will be awarded for:

1st Place Team, 2nd Place Team, Last Place Team  
 Closest to the Pin, Longest Drive, and Hole in One  
 (We had a Hole in One winner in 2007!)

### Registration Fees:

**\$125.00** per person (if received by May 20, 2009)  
**\$150.00** per person (after May 20, 2009)

Please fill out the form below and return to your D.A.D.S. representative or team captain with your payment information. You can also e-mail information to [dadsgolf@gmail.com](mailto:dadsgolf@gmail.com) or fax it to the DSI office at: 317-925-7619.

**Team Captain** (golfer 1):  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_ State: \_\_\_\_\_  
 Zip: \_\_\_\_\_ Phone: (\_\_\_\_) \_\_\_\_\_  
 E-Mail: \_\_\_\_\_

**Golfer 2:**  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_ State: \_\_\_\_\_  
 Zip: \_\_\_\_\_ Phone: (\_\_\_\_) \_\_\_\_\_  
 E-Mail: \_\_\_\_\_

**Golfer 3:**  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_ State: \_\_\_\_\_  
 Zip: \_\_\_\_\_ Phone: (\_\_\_\_) \_\_\_\_\_  
 E-Mail: \_\_\_\_\_

**Golfer 4:**  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_ State: \_\_\_\_\_  
 Zip: \_\_\_\_\_ Phone: (\_\_\_\_) \_\_\_\_\_  
 E-Mail: \_\_\_\_\_

One of the goals of D.A.D.S. is to provide educational and recreational opportunities for individuals with Down syndrome. Proceeds from this year's outing will be used in part to support Camp Hi-Lite, which provides week-long camp sessions exclusively for individuals with mental and physical disabilities. Thank you for your generous support!



# SPONSORSHIP LEVELS

Each year the D.A.D.S. golf outing welcomes over 300 golfers. Sponsorship of the outing not only gives you an opportunity to help a very worthy charity, but it also puts your company's name in front of hundreds of professional men and women who share your interest in the cause.

- Camp Sponsor:** ..... \$100
- Hole Sponsor:** ..... \$200  
Includes Hole Sign
- Beverage Cart Sponsor:** ..... \$500  
Includes Signage on Beverage Cart
- Bronze Sponsor:** ..... \$1,000  
Includes 1 Plaque, 2 Hole Signs, Inclusion on Banner\*
- Silver Sponsor:** ..... \$1,500  
Includes 1 Plaque, Foursome, 2 Hole Signs, Inclusion on Banner & Some Printed Material\*
- Gold Sponsor:** ..... \$2,500  
Includes Plaque, Foursome w/Hats & Shirts for Each Golfer, 2 Hole Signs, Inclusion on Banner & All Printed Material\*, Plus Special Recognition at the Event
- Platinum Sponsor:** ..... \$5,000  
Includes Plaque, 2 Foursomes w/Hats & Shirts for Each Golfer, 4 Hole Signs, Inclusion on Banner & All Printed Material\*, 4 raffle tickets (for big screen plasma TV) Plus Special Recognition at the Event

\* Payment must be received by April 6, 2009

### Sponsorship Contact Information:

Company Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_  
 State, Zip: \_\_\_\_\_  
 Contact Name: \_\_\_\_\_  
 Phone: \_\_\_\_\_  
 E-mail: \_\_\_\_\_  
 Company www: \_\_\_\_\_

Gold & Platinum Sponsors, please provide a high-resolution digital file of your company logo to [dadsgolf@gmail.com](mailto:dadsgolf@gmail.com).

# PAYMENT INFORMATION

- Golfer Fees Only
- Sponsorship Fees Only
- Golfer Fees AND Sponsorship Fees Combined
- My check is attached/enclosed
- Please Charge My: Visa / Master Card / Am Express

Name on Card: \_\_\_\_\_  
 Exp. Date: \_\_\_\_\_  
 Card No. \_\_\_\_\_  
 Signature: \_\_\_\_\_

Total: \$ \_\_\_\_\_

Make check payable to:

D.A.D.S. Golf Tournament c/o DSI  
 3050 N. Meridian Street  
 Indianapolis, IN 46208

**Federal Tax ID#: 35-1957015**

Please NOTE: There will be no refunds, although substitutions are welcome at any time.

# Dads Appreciating Down Syndrome



*"We came together for our kids. We stay together for each other."  
Ray, father of Katy, 6*

*Pictured are Jeff Simmons, Bart Adkins, and Bill Clark*

Dads Appreciating Down Syndrome, or D.A.D.S., is an organization of fathers of children who happen to have Down syndrome. We hesitate to call our self a "support group", even though we do, in many ways, support each other. We prefer to think of D.A.D.S. as an "action group." You won't find us in a church basement drinking warm coffee and whining about having children with Down syndrome. Instead, you'll find us out in the community coaching our kid's sports teams, participating in our children's IEPs, volunteering at local Down syndrome fundraising events, and even sponsoring fundraising events of our own.

We host regular meetings where our members come together to share insights and experiences. Face it: there are certain responsibilities that generally fall on the shoulders of the father. Having a child with special needs often affects how we approach those responsibilities. We invite expert speakers to discuss medical, educational, financial, social, and many other issues that affect our children's lives. And of course, we share stories and experiences that are unique to fathers of children with Down syndrome. Your colleagues at the office may not understand your excitement when your 5 yr old makes "poopie" on the toilet for the first time, but other D.A.D.S. will, because we've all been there.

## Can we talk?

Dads Appreciating Down Syndrome — D.A.D.S. Indiana group info

To join our Indiana online group visit:  
<http://health.groups.yahoo.com/groups/dads/in>  
click on "Join This Group" then follow instructions

To join our National online group visit:  
<http://groups.yahoo.com/groups/dads>  
click on "Join This Group" then follow instructions.



## D.A.D.S. Lifetime Fitness Family Fun Events

Saturday April 11, 2009  
Saturday May 9, 2009  
Saturday June 13, 2009

Join us from 2:00-5:00 p.m.

Join D.A.D.S. for a family evening of fun including pizza, swimming, rock climbing, gym games, and other activities.

This is a free event. To RSVP call 317.925.7617 email us at [register@indianadsf.org](mailto:register@indianadsf.org). Please include all attendees names and ages.

This event will be held at:  
Lifetime Fitness  
8705 Castle Creek Parkway,  
Indianapolis, IN 46250

## D.A.D.S. Monthly Meeting

D.A.D.S. meet the 2nd Tuesday of each month, 6:30pm, at Loon Lake Lodge, on East 82th Street, just off I-69, on the north eastside of Indianapolis.

Loon Lake Lodge  
6880 E. 82nd St.  
Indianapolis, IN 46250

## D.A.D.S. Fishing Day Saturday April 25th, 2009 from 12:00-5:00p.m.

Join D.A.D.S. for family fun day fishing at Bradford Woods.

**Location:** Bradford Woods, 5040 State Road 67 N, Martinsville, Indiana 46151

For more information about this event contact Ray Glowner at 317-319-8795 or [rayglowner@sbcglobal.net](mailto:rayglowner@sbcglobal.net).

## RSVP

If you would like to attend this event, please email us at: [register@indianadsf.org](mailto:register@indianadsf.org) or by phone at 317-925-7617. Please be sure to include the first and last names and ages of all attendees.

For more information about D.A.D.S. or D.A.D.S. events please contact Ray Glowner at: [rayglowner@sbcglobal.net](mailto:rayglowner@sbcglobal.net)

Visit us on the web at:  
[www.dadsnational.org](http://www.dadsnational.org)

## Ask the Expert

### Recurrence Risk for Down Syndrome

Many parents of children with Down syndrome desire to have additional children. However, they may be hesitant to do so because of their concerns about the recurrence for Down syndrome in future pregnancies. This article discusses these risks based on the specific cause of the Down syndrome and the age of the mother at the time of any subsequent pregnancy.

### Causes of Down Syndrome

#### Trisomy 21

The majority of individuals with Down syndrome have trisomy 21, i.e., three copies of the 21st chromosomes and a total of 47 chromosomes in each of their cells. Normally, there are only two copies of chromosome 21 in each of the cells of an individual. In Down syndrome, all three chromosome 21s are “normal” 21st chromosomes but because of the extra chromosomal material, the individual has Down syndrome. Approximately 94% of individuals with Down syndrome have trisomy 21.

#### Mosaic Down Syndrome

A second form of Down syndrome, which accounts for approximately 3% of diagnosed cases, is mosaic Down syndrome (mosaic trisomy 21). With this type of Down syndrome, some cells in the individual have trisomy 21, while other cells have a normal chromosomal constitution (46,XX in females and 46,XY in males). Mosaic Down syndrome occurs in two ways. The first is when trisomy 21 is present at conception. Subsequently, one copy of chromosome 21 is lost during cell division resulting in a cell line with a normal chromosomal make-up. The percentage of normal cells in the individual will depend on when after conception this chromosomal loss occurred. A second cause of mosaic Down syndrome occurs in the reverse fashion. Here, the conception begins with a normal chromosomal make-up, but an error occurs during cell division that results in the retention of a chromosome 21 and a cell line with trisomy 21. The length of time after conception when this error occurs again will determine the percentage of trisomic cells present in an individual.

#### Robertsonian Translocations

A third mechanism which produces Down syndrome is known as a Robertsonian translocations. In this particular type of Down syndrome, the long arm of chromosome 21 attaches to the long arm of another chromosome, usually at the centromere (the centromere is the structure in the chromosome that separates the long arm from the short arm of the chromosome, and is involved in chromosome separation during the cell division). If an individual has this translocation plus two normal chromosome 21s, he or she will have Down syndrome even though the person only has a total of 46 chromosomes. The most common Robertsonian translocation causing Down syndrome is a translocation between chromosomes 14 and 21; other less common translocations are 13;21, 21;21 and 21;22.

#### Recurrence Risk

The recurrence risk for a couple who previously has had a child with Down syndrome is related to the specific cause of the Down syndrome in their child. The following information relates to the reoccurrence risk associated with each form of Down syndrome. Trisomy 21:

- (approximately) 1% until the mother’s age related risk exceeds 1%, which is age 41 or older.
- Age related risk for mothers 35 years old is ~1 in 385; for age 40 – 1 in 110, and for age 45 – 1 in 28.

Age-related risks at any woman’s age are available. Contact your local genetic counselor or clinical geneticist for more specific details.

#### Mosaic trisomy 21:

- Undetermined but probably less than 1%, or the maternal age-related risk.

#### Robertsonian 13;21 translocation:

- The risk of one parent carrying this translocation has not been determined.
- If the mother carries the translocation, the recurrence risk appears to be between 10-17%.
- If the father carries the translocation, the recurrence risk appears to be ~1%.
- If neither parent carries the translocation, the recurrence risk probably is less than 1% or the maternal age risk.

#### Robertsonian 14;21 translocation:

- In this situation, there is a 50% chance that one parent carries a balanced Robertsonian 14;21 translocation.
- If the mother carries the translocation, her chance of having a subsequent child with Down syndrome is ~ 10%.
- If the father carries the translocation, the risk is ~2%. Why this difference occurs is unknown.
- If neither parent carries the translocation, the recurrence risk probably is less than 1% or the maternal age risk.

#### Robertsonian 21;21 translocation:

- When this translocation is the cause of the child’s Down syndrome, there is ~4% risk that one parent is a balanced 21;21 Robertsonian translocation carrier. If this is the case, then the chance for having a child with Down syndrome with any additional pregnancy is essentially 100%, ie, essentially all subsequent live born children of theirs would have Down syndrome, regardless of which parent carries the translocation.
- If neither parent carries the translocation, the recurrence risk probably is less than 1% or the maternal age risk.
- Some parents have been found to be mosaic carriers for this Robertsonian 21;21 translocation and could have an increased recurrence risk for Down syndrome.

#### Robertsonian 21;22 translocation:

- If one parent carries the translocation, the recurrence risk appears to be ~4%.
- If neither parent carries the translocation, the recurrence risk probably is less than 1% or the maternal age risk.

## Further Information

For additional information or answers to questions concerning the above information or to arrange for genetic counseling, contact your local genetics center. In central Indiana, one may contact the Department of Medical and Molecular Genetics, Indiana University School of Medicine at (317) 274-1057, or St. Vincent Medical Genetics and Neurodevelopmental Center at (317) 338-5288.

David D. Weaver, M.D.  
Department of Medical and Molecular Genetics  
795 W. Walnut Street  
Indiana University School of Medicine  
Indianapolis, Indiana 46202-5251



Best In Sight Eye Care has once again had the pleasure of meeting and providing eye care services for an exceptional young man. His name is Thomas Smith, who is an active and delightful 11 year old who happens to have Down syndrome. He attends Nativity Catholic Church and loves swimming and playing softball. He has played in the Franklin Township Challenge League for the past 4 years and loves to play with his helper and smile at the crowd as he is running the bases. If you need a ride on the golf cart, Thomas will gladly take you where you need to go, for he has recently learned to drive the golf cart by himself!



Thomas has had some health issues (including a heart defect that spontaneously closed on its own when he was 3) but overall "we have been very lucky" reports Thomas' mother, Mary. "Thomas is very active and loves to be outside and play with his brother and sister. He thinks anything they do, he can do, and we try very hard to allow that to happen."

"Recently we discovered an eye doctor's office that not only has a great frame line that helps Thomas see well through all his activities, but also provides incredible service. Unfortunately I find it is rare that people with disabilities are treated with dignity and respect. I so appreciated that Best In Sight Eye Care gave my beautiful son the dignity and respect that he and others like him so deserve. From the moment we entered the office, everyone treated Thomas like a "real" person—the doctor and his entire staff spoke to Thomas directly (and not to me like too often is the case).

Thomas felt very important and knew that he was someone special there. He especially bonded with his optician, Mark Parks. Thomas had a great time hanging out with him and felt very comfortable. I walked out of Best In Sight and felt in my heart that maybe "change" is coming and there is hope yet for this crazy world", says Thomas's mom, Mary.

Thomas loves his new glasses, mainly because he doesn't have to constantly push them back up on his face. This leads to fewer fingerprints on his lenses, too. He can actually see out of them and doesn't have to look over the top. Thomas also likes all the attention he is getting with his new "cool" glasses. He is such a ham!

According to Best In Sight Eye Care, (which is currently the only practice in Indianapolis that carries SPECS 4 us frames) this frame line is designed specifically to fit the facial features common to children with Down syndrome. The frames have a lower and wider bridge, which allows the frames to stay on and look good so that kids are looking through the lenses, not over them.

"The Specs 4 Us frame line, with its innovative design, is long overdue," states Dr. Huffman. "By the age of 3, over 80% of kids with Down Syndrome will need glasses to correct their vision. Because of their unique facial features, they have often been fit with the correct lenses, but unfortunately, not the best frames that actually allow them to see through the lenses correctly."

Even though Thomas' mom, Mary, wrote to Best in Sight "thank you from the bottom of my heart," Dr. Huffman speaks for the entire staff when he replies—"No...thank YOU. We enjoy providing eye care for all of our patients, but it is truly a privilege and honor to provide this service for these exceptional individuals and their families. There is enough that these kids and their families have to go through and we think that a trip to the eye doctor shouldn't be just another thing that they have to "deal" with. Instead, we hope to provide an experience that they will not only enjoy....but actually look forward to!"

For more information about the SPECS 4 us frame line, please contact Best In Sight Eye Care at 317-782-4000 (Indianapolis); 317-861-4100 (New Palestine) or at [www.BestInSightEyeCare.com](http://www.BestInSightEyeCare.com).



## New site offers disability news

By Beth DeHoff

If you're looking to find new information or an understanding format for special needs topics, check out my new "beat" as a reporter for [www.examiner.com](http://www.examiner.com). I'm the Indianapolis special needs parenting reporter, and I post new stories three or four times a week at <http://www.examiner.com/x-3598-Indianapolis-Special-Needs-Kids-Examiner>.

Down Syndrome Indiana is a featured organization on my page, and so are other organizations. I try to cover any programs and activities coming up in the Indy area that would be of interest to families of a person with a disability. I also try to inject my own experiences and perspective, which makes this some kind of cross between news reporting and a blog. Readers can leave comments and talk with one another, and I often use reader suggestions for stories. I hope this format can become an interactive, online information source and social gathering for parents of children and adults with special needs.

I make the point in one of my articles that, as parents of a child with Down syndrome, autism, and late effects from leukemia treatment, we're in a lonely place. We don't know anyone else dealing with all three of these issues in one child. But really, that is just one aspect of how alone parents can get to feeling. I have to wonder if that's common even in the Down syndrome community, even with a great group like Down Syndrome Indiana to support us.

In the Down syndrome community, we tend to fall in love with potential. I don't want to make generalities, but face it, our kids are cute, and the items populating most Down syndrome news stories involve "wonder kids" who play on their school's team, are elected homecoming king or queen, head off to college, hold a job, travel the nation doing speaking engagements, and/or marry. All of those stories are wonderful, but it can leave some families feeling a bit alone, struggling in special education systems, overwhelmed by medical appointments, unable to hold a genuine conversation with their much-loved but mostly nonverbal child.

That's why I think it is helpful sometimes to hang out with people who have other disabilities, as well as our closer family of kids with Down syndrome and their families. My Westside Special Needs Network of Speedway UMC is for people with any kind of disability and their families; FUSE is a similar organization on the Eastside. I genuinely enjoy the company of people with autism, cerebral palsy, and many other diagnoses. I enjoy chatting with their families. I love to see the compassion and friendship people with Down syndrome so readily offer people with other disabilities. They have it right, I think. Why not expand our knowledge and compassion with families who have other special needs? Why not join forces with these families for a larger, louder voice on behalf of people with disabilities when it comes to school, community and government challenges?

I'm a writer and a journalist, and I am passionate about disability rights and access. Those are some of the neat and tidy reasons I'm now a special needs reporter for [examiner.com](http://www.examiner.com). But the most compelling reason I'm doing this is to help build an Indianapolis area community among people with all sorts of disabilities and their families. In the first article's comments section, I had notes from parents of children with Down syndrome, autism, and mitochondrial disease, as well as comments from service providers and a handful of friends with no disability experience at all who just wanted to learn more. That, I believe, is the way the world should work. So come on in and join the discussion.

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## Rebecca's Story

By Cyndi Johnson

I will never forget that life-altering week in February of 2007. I was pregnant with my second child and had opted to undergo prenatal testing because I was over 35—the maternal age at which fetal defects increase significantly. I had just entered the 2nd trimester and was starting to come out of the morning sickness fog. When the phone rang that Monday morning, I figured it was the usual—one of my friends calling to invite my active 1-year-old and me for a spontaneous play date. I was surprised to hear the voice of the kind, upbeat genetic counselor with whom my husband and I had met weeks before during the prenatal testing process. I greeted her and then waited expectantly for her to congratulate me on a healthy pregnancy with all test results having returned negative. Instead her tone was decidedly different from our face-to-face meeting as she said in a choked voice, "I'm afraid I have some bad news." The test results showed a 1-in-6 chance of Trisomy 18 and a 1-in-5 chance of Trisomy 21 (Down syndrome), and she recommended that I have an amniocentesis the following day.

I proceeded with the amnio on Tuesday without incident. Then on Wednesday, on the front page of the local newspaper was a photograph of a beautiful elementary-aged girl with Down syndrome and an inspiring article featuring her family and highlighting a new Down syndrome parent network in town that was to have its first public event that Friday evening. So on Thursday, when the genetic counselor called to inform us that we were to have a little girl with Down syndrome, I had already made up my mind to attend.

Throughout that spring as I tried to prepare for my daughter's birth by reading everything about Down syndrome that I could get my hands on, there were many moments of intense emotion. Even in the midst of the joy I felt when my baby girl would kick or hiccup inside my ever-expanding belly, there remained a nagging ache in my heart. I grieved the loss of the family I had always imagined. I was deeply concerned about the medical problems my daughter might endure. I was saddened at the thought of the struggles she would face to be accepted and included in a society that many of us take for granted. But most of all I was heartbroken with the thought that my child would likely never have children of her own, that my family tree would have a fruitless branch. The sense of loss I felt over my "stunted" family tree was punctuated against the new life of spring as the trees in my own back yard were bursting with buds and blooms and new branches.

Summer came, and so did my baby girl. After months of preparation for both my head and my heart, and the better part of the healing process behind me, Rebecca Ann was born. Named after my mother and myself, Rebecca also shares my stubbornness and determination! She has my mother's red hair and my father's piercing blue eyes. I tell many people that early in my pregnancy I actually

“put in an order” for a girl with red hair, although I didn’t order the extra chromosome. But Rebecca was a package deal, and despite all the medical challenges that continue to arise, she has truly been a treasure. I can say with full honesty that I would not change anything about her, although I sometimes wish I could change how the world might later receive her. It is easy to adore a red-headed baby girl with pigtails, but as Rebecca grows older she may find acceptance harder to come by.

Two years have passed, and spring is again upon us. The days are growing warmer and longer, and the crocuses and daffodils will soon be poking up through the ground. The trees will begin again their cycle, budding and blooming and branching. And I am reminded of how my family tree continues on, and that Rebecca is an essential part of its life.

In fact, I am pleased to say that I was wrong about Rebecca’s branch of our family tree, as she has found unexpected ways to make her own branch quite fruitful indeed! Remarkably, she managed to graft a long lost branch back into our family tree. My estranged father, whom I had not seen in years, must have sensed some solidarity with Rebecca and came to her open heart surgery last May, almost 18 years to the day after his own heart transplant. And Rebecca’s timing was impeccable because my father lost his wife of 24 years in October, and we were there to offer what comfort we could at her passing. He has agreed to stay in touch and even visited on Christmas.

Rebecca has also found ways to nourish the entire tree from her tiny little branch. Family members from near and far have been tremendously supportive, from the moment of the diagnosis, through all her surgeries and medical challenges, and even into the future with their generous contributions to a “life fund” established for her. And even before Rebecca was born, my husband’s aunt in Oregon designed a quilt for Rebecca, with each of 34 pieces crafted individually by our family and friends from across the United States. That quilt hangs on the wall above Rebecca’s crib where she sleeps beneath it every night, beneath all the love and care that went into creating it. She continues to be enveloped in that love and care, and she likewise envelopes others in the warmth of her smile and sweet spirit.

And finally, Rebecca’s branch has an uncanny way of bringing people together. From the moment I read that front-page article about the young girl with Down syndrome, I realized that while I could probably manage this journey on my own, I would much rather walk alongside others with whom I might share experiences, wisdom, joys, challenges, and friendship. There are many wonderful persons I may never have met without Rebecca’s inspiration, friends who have become like family—yet another one of her means of “growing” the family tree.

I have full faith that Rebecca’s branch will continue to grow, delight, and surprise. And our family tree is the better for it.

Cyndi is on the Board of Directors of the Down Syndrome Family Connection (DSFC), serving the Bloomington area since 2006.



### Jessica’s Circle Look Over the Rainbow

It is always important to look at the person and their abilities, and then you look at their disability. My family has always celebrated my disability and they also look at the happy side. Individuals with special needs should be allowed to have a relationship whether it is local or long distance; many individuals should be allowed to make their own decisions and choices for themselves.

I think being a self advocate for all individuals is very important to me because I love to make a difference for families and individuals with special challenges like me. You should always keep in mind that the more you look over the rainbow the happier you get.

I always want many self advocates and individuals to keep in mind that if you want to feel good and look good you have to believe in yourself.

### Kudos To A Single Parent By Donna Hammock

Single parenting is probably the most challenging experiences to deal with. Raising a child with Down syndrome is almost more challenging than two parents can handle let alone one. I know of one such single parent. Larry Miller who is single and raising his young 6 ½ year old, Kevin. Larry sets a great example of single parenthood for all who share in the joy of having a child with Down syndrome. It is no surprise to see Larry in a circle of moms sharing his techniques for preparing gluten-free meals for Kevin who also has celiac disease, or in that same group of moms giving advice on a great formula for potty training. If you were to ask Larry if he would change anything, he’d tell you he would have it no other way. So what makes Larry’s situation so unique? Because being a single parent to Kevin has changed Larry’s life and made it a completely positive experience for the better. Not only is Kevin thriving, but Larry as well.

So, for all parents who are single and raising a family, I say Kudos to you! And you Larry, you’re doing a great job.



## Danny the Waiter

By Kathy R

The other night, Danny (10) wanted his older brother Nathan to watch a Tom and Jerry cartoon with him..Nathan told him that he was busy, so Danny thought for a little bit, then came back in the room with a dish towel over his arm, and a pad of paper/pencil ...told Nathan that he wanted to play 'restaurant' ....so Nathan said, 'ok'

**Danny:** "You have to go in there" (the room where he wanted to watch Tom and Jerry)

**Nathan:**(figuring that Danny was up to something, but curious to see what it was, went into that room)

**Danny** (in his 'waiter' voice): "What do you want to eat?"

**Nathan:** "What is on the menu?"

**Danny:** "Watoh"(water)

**Nathan:**"Ok, could I please have some water?"

Danny runs to get Nathan a nice glass of ice water, brings it back, then says, "Ok, your turn to be the waiter."

**Nathan the Waiter:** "Ok,,,would you like some water, too?"

**Danny:**"No, I want pizza and pop."

## Reflections of Erin

The Importance of Belonging, Relationships, and Learning with Each Other

When the inclusive education movement began several years ago, many used the argument that it was purely for social benefits. The curriculum used for children with disabilities that were placed in general education classrooms was often very different from what was being taught in those classrooms. Slowly the movement began to stress the importance of accessing the curriculum and making accommodations, modifications, or enhancements as needed so that ALL students could learn together.

In recent years the focus has been on academic standards and identifying deficits, which has often led to more sorting, pull-out, and remediation for a variety of students, including those with disabilities, rather than inclusive classrooms and schools. The importance of discovering the gifts of each person, developing relationships, and embracing our interdependence are often not considered as valid in evidence-based research and standards, curriculum development, or instructional practices.

Barbara McKenzie hopes to shift the focus back to creating inclusive learning communities by sharing evidence that she and others have gathered from the experience of knowing and loving Erin. Conveyed in the form of keen observations, heartfelt surprises, and insightful reflections, the stories and images inspired by Erin McKenzie's life demonstrate the rich connections and relationships that result from an inclusive learning community.

For more information about this book visit: <http://www.candeebasford.com/Erin.htm>



## Volunteer Opportunities at DSI

DSI is now offering volunteer orientation sessions to help our volunteers feel more welcome and comfortable! We are also adding weekend workdays to accommodate those volunteers who want to donate their time but have other commitments during the week. There are always opportunities for valuable volunteer time at DSI.

For more information email: [volunteer@indianadsf.org](mailto:volunteer@indianadsf.org) or give us a call at: 317.925.7617. We welcome and appreciate our volunteers of all ages and abilities. Thank You to all DSI volunteers. We appreciate your time and abilities.

## Cuenta Conmigo

El grupo de apoyo para familias de niños con Síndrome de Down.

Les invita a que participen a la reunión mensual. Tendremos presentadores especializados en el tema. Participe en la educación de sus hijos compartiendo con otras familias sus conocimientos, inquietudes y el deseo de aprender como ayudarle a su hija en su aprendizaje y a crecer saludablemente. Habrá cuidado de niños.

Dónde: Down Syndrome Indiana  
3050 N Meridian Street  
Indianapolis, In 46208

Se puede estacionar en el Museo de Niños en el espacio marcado "Reserved for Junior League" ó detrás de la oficina.

Hora: 6:00-7:30 p.m.

Fecha: Abril 1, 2009 and Mayo 6, 2009

Si desea más información por favor llame a: Rita Cano 226-4743 ó 408-2633

¡Les esperamos!

## Join the Birthday Club!



If you are an individual with Down syndrome, or the parent of a young child with Ds, and would like to receive a birthday card from DSI, please e-mail us at: [info@indianadsf.org](mailto:info@indianadsf.org) or call 317-925-7617. Please be sure to provide the individuals first and last name, address, and date of birth.



Danny

If your family has photos you would like to share please email the photo, along with information about photo to: [idsffice@indianadsf.org](mailto:idsffice@indianadsf.org)



Self Advocates at the Karen Gaffney Event



MaCayla



Evan



Whitney



Self Advocates Bowling Event



Front (L-R): Jessica Green, Mark Hublar, Lisa Torkaz-Gutierrez Back (L-R): Joe Meares, Nina Fuller, Kathy Ratkiewicz, Senator Sam Brownback *AIA article page 1/2*

## Indiana Governor, Senator, and Legislature Contacts

This information is provided as a compliment to the article "Down Syndrome Advocates from Across the US Visit Capitol Hill" on pages one and two of this edition of Common Bonds.

### Sen. Richard Lugar (R-IN)

1180 Market Tower, 10 West Market Street  
Indianapolis, Indiana 46204  
Phone: (317) 226-5555  
Fax: (317) 226-5508  
Email: [senator\\_lugar@lugar.senate.gov](mailto:senator_lugar@lugar.senate.gov)

### Sen. Evan Bayh

1650 Market Tower, 10 West Market Street  
Indianapolis, IN 46204  
Phone: (317) 554-0750  
Fax: (317) 554-0760  
Email: [senator@bayh.senate.gov](mailto:senator@bayh.senate.gov)

### Rep. Peter Visclosky (D-IN 1st District)

13th term Democrat from Indiana 1st District.  
7895 Broadway, Suite A  
Merrillville, Indiana 46410  
Phone: (219) 795-1844  
Fax: (219) 795-1850

### Rep. Joe Donnelly (D-IN 2nd District)

207 West Colfax Avenue  
South Bend, Indiana 46601-1601  
Phone: (574) 288-2780  
Fax: (574) 288-2825

### Rep. Mark Souder (R-IN 3rd District)

8th term Republican from Indiana 3rd District.  
1300 South Harrison Street, #3105  
Ft. Wayne, Indiana 46802  
Phone: (260) 424-3041  
Fax: (260) 424-4042  
[souder@mail.house.gov](mailto:souder@mail.house.gov)

### Rep. Steve Buyer (R-IN 4th District)

100 South Main Street  
Monticello, Indiana 47960  
Phone: (574) 583-9819  
Fax: (574) 583-9867

### Rep. Dan Burton (R-IN 5th District)

8900 Keystone at the Crossing, #1050  
Indianapolis, Indiana 46240-7646  
Phone: (317) 848-0201  
Fax: (317) 846-7306

### Rep. Mike Pence (R-IN 6th District)

1134 Meridian Plaza  
Anderson, Indiana 46016  
Phone: (765) 640-2919  
Fax: (765) 640-2922

### Rep. Andre Carson (D-IN 7th District)

300 East Fall Creek Parkway, #300  
Indianapolis, Indiana 46205  
Phone: (317) 283-6516  
Fax: (317) 283-6567

### Rep. Brad Ellsworth (D-IN 8th District)

101 NW Martin Luther King, Jr. Boulevard, Room 124  
Evansville, Indiana 47708  
Phone: (812) 465-6484  
Fax: (812) 422-4761

### Rep. Baron Hill (D-IN 9th District)

279 Quartermaster Court  
Jeffersonville, Indiana 47130  
Phone: (812) 288-3999  
Fax: (812) 288-3873

## DSI Family & Event Photos

## Community Events

### April

#### Self Advocates Meeting

**Wednesday, April 8th, 2009 from 11:00 a.m. - 2:00p.m**

Studio Tour of WISH-TV Channel 8 & Lunch at Side Street Deli. We will meet at the DSI office at 11:00 am and be back to the DSI office by 2:00 pm.

This is a FREE event for our Self Advocates!

To register email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. For more information about this event contact Rachel Lowe at: [info@indianadsf.org](mailto:info@indianadsf.org)

#### D.A.D.S. Lifetime Fitness Family Fun Event

**Saturday April 11, 2009 from 2:00-5:00 p.m.**

Lifetime Fitness, 8705 Castle Creek Parkway, Indianapolis, IN 46250

Join D.A.D.S. for a family evening of fun including pizza, swimming, rock climbing, gym games, and other activities. There is no charge for this event, D.A.D.S. will be picking up the tab.

To register email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. Please be sure to include the first and last names and ages of all attendees.

#### D.A.D.S. Fishing Day

**Saturday April 25th, 2009 from 12:00-5:00p.m.**

Join D.A.D.S. for family fun day fishing at Bradford Woods, 5040 State Road 67 N, Martinsville, Indiana 46151

For more information about this event contact Ray Glowner at 317-319-8795 or [rayglowner@sbcglobal.net](mailto:rayglowner@sbcglobal.net). To register please email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. Please be sure to include the first and last names and ages of all attendees.

#### Special Needs Family Resource & Information Fair

**Saturday, April 25, 2009 10 a.m. to 2 p.m.**

This 4th annual fair features approximately 50 service providers and vendors serving children, youth and adults with disabilities. Includes information booths and mini carnival - free! - and optional lunch for a small charge. An invaluable source of information on community resources, from waivers to therapies to social programs to education and much more.

Speedway United Methodist Church, 5065 W. 16th St., Indianapolis. Call 317-971-2619 to reserve free child care or request Spanish language interpreter.

#### Eastside Mom's Night Out

**Tuesday, April 28, 2009 time to be announced**

Mom's join us to get out of the house, meet other mom's, share stories, great ideas, and have a good time! Details about this event will be available on the parent loop soon! For more information call us at 317-925-7617 or by email [info@indianadsf.org](mailto:info@indianadsf.org)

### May

#### Self Advocates Meeting

**Tuesday, May 5th, 2009 from 6:00-8:00**

Outback Steakhouse (Location next to Castleton Mall)  
5771 East 86th Street, Indianapolis, IN 46250

This is a FREE event for our Self Advocates! Gluten free menu!

To register email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. For more information about this event contact Rachel Lowe at: [info@indianadsf.org](mailto:info@indianadsf.org)

#### D.A.D.S. Lifetime Fitness Family Fun Event

**Saturday May 9th, 2009 from 2:00-5:00 p.m.**

Lifetime Fitness, 8705 Castle Creek Parkway, Indianapolis, IN 46250

Join D.A.D.S. for a family evening of fun including pizza, swimming, rock climbing, gym games, and other activities. There is no charge for this event, D.A.D.S. will be picking up the tab.

To register email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. Please be sure to include the first and last names and ages of all attendees.

#### Down Syndrome Indiana 2009 Annual Meeting

Join us on Tuesday May 19th, 2009 at 6:00 p.m. for our annual meeting. Details about this event can be found on page 13.

#### 4th Tuesday Parent Group meeting at St. Luke's

Tuesday, May 26th, 2009

Topic: Medicaid Waivers -The Bureau of Developmental Disabilities Services (BDDS) will be speaking. Adrienne Shields, DDRS Deputy Director, Kellie Calita, BDDS Director of Client Services, and Kelly Scott, BDDS Targeting Specialist will be our speakers.

Location: **St. Lukes United Methodist Church, Fellowship Hall, 100 W 86th St**, Indianapolis, IN 46260

To register email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. Please be sure to include the first and last names and ages of all attendees. Childcare will be provided if requested when RSVP is provided.

#### The 7th Annual D.A.D.S. Golf Outing

**Friday, May 29, 2009**

Location: Pebble Brook Golf Course, 110 Westfield (St Rd 32) Noblesville, Indiana 46062

*Details about this event can be found on pages 3 and 4.*

### June

#### Self Advocates Meeting

**Tuesday, June 2nd, 2009 from 6:00-8:00**

This event will be an informational meeting with a speaker from Noble of Indiana about the different programs that they offer .

To register email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. For more information about this event contact Rachel Lowe at: [info@indianadsf.org](mailto:info@indianadsf.org)

#### Indianapolis Executive Airport & Montgomery Aviation Fly In

**Saturday June 20th, 2009 from 10:00 - 3:00 p.m.**

New and exciting surprises this year! Skydiving performance at 1:00 p.m! Please note airspace will be closed from 12:45 - 1:15 p.m.

For more information view the flier at: [http://www.dsindiana.org/docs/fly\\_in\\_flyer2009.pdf](http://www.dsindiana.org/docs/fly_in_flyer2009.pdf)

#### Westside Mom's Night Out

**Tuesday, June 23, 2009 time to be announced**

Mom's join us to get out of the house, meet other mom's, share stories, great ideas, and have a good time! Details about this event will be available on the parent loop soon! The host will be Stephanie Glowner. For more information call us at 317-925-7617 or by email [info@indianadsf.org](mailto:info@indianadsf.org)



#### DSI Family Picnic

**Sunday June 28, 2009 from 12:00 noon - 4:00 pm**

Please join us on Sunday, June 28th, 2009 for lots of food, fun, and togetherness. This year's picnic will provide the same amazing food as last year (gluten free menu will be available). Activities will include water games (bring swim-suits), balloon twisting, and spray tattoos. **Come Rain or shine! We look forward to seeing you there!**

12:30 p.m. Lunch Served  
12:00 noon - 2:00 pm Quiet Time  
2:00 - 4:00 pm Musical Entertainment TBD

Location: Oak Hill Mansion, 5801 E 116th St, Carmel, IN 46033  
(317) 843-9850 [www.oakhillmansion.com](http://www.oakhillmansion.com)

To register email: [register@indianadsf.org](mailto:register@indianadsf.org) or 317-925-7617. Please be sure to include the first and last names and ages of all attendees.

# Down Syndrome 2009 Annual Meeting



Join us on Tuesday May 19th, 2009 at 6:00 p.m. for our annual meeting. Doors open at 6:00 p.m. Light refreshments will be served. The program begins at 6:30 p.m. Our speakers this year will include Tom O'Neill and Joe Bockerstette. If you would like to nominate someone for a Star Award please email your nomination to: [register@indianadsf.org](mailto:register@indianadsf.org). Staff and Board Members are excluded. Deadline for nominations is April 30th.

**Location:** Riley Hospital Outpatient Center Lilly Auditorium, 702 Barnhill Rd, Indianapolis, In 46202

Parking for this event is available at the Riley Outpatient Center located at: 575 West Drive, Indianapolis, IN 46206 Parking Passes will be provided to attendees.

Reserve your seat now! Space for this event is limited. To register for this event email us at: [register@indianadsf.org](mailto:register@indianadsf.org) or by phone at 317-925-7617.

Childcare is available. If you are in need of childcare, please email us at: [register@indianadsf.org](mailto:register@indianadsf.org) or by phone at 317-925-7617. When registering please provide your child's name and age.

## Down Syndrome Indiana Star Awards

Down Syndrome Indiana honors individuals, corporations, or groups whose achievements or contributions further our mission. A subcommittee of representatives from the Board of Directors determine award recipients. Current Board members are ineligible.

### Why a Star?

A star was chosen to represent the Down Syndrome Indiana for several reasons:

#### Focus

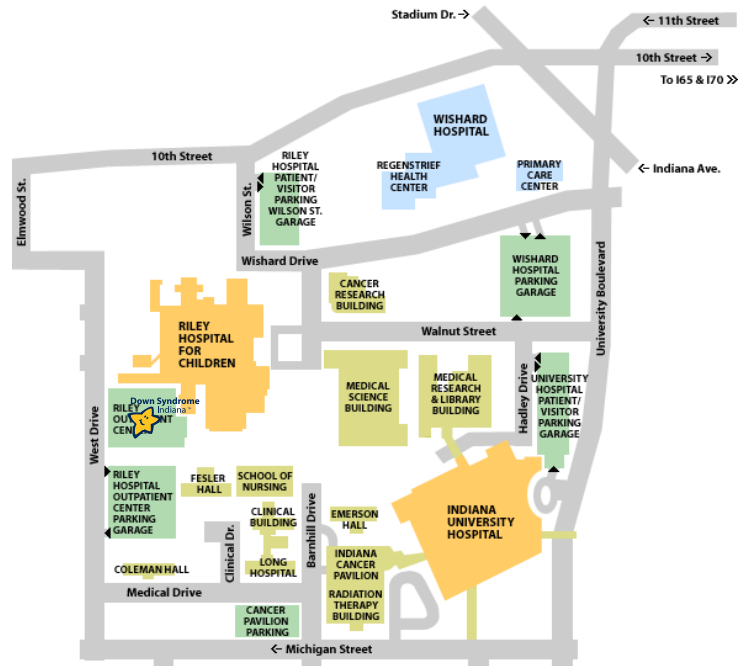
Parents, siblings, educators, and other friends and family often describe individuals with Down syndrome as "stars" or the center of attention. The star logo recognizes that quality, and reminds us of our need to challenge ourselves and society to see all individuals with Down syndrome for their contributions to their community.

#### Achievement

A star has long been a symbol of achievement. The star logo reminds us of the importance of all "achievements" of individuals with Down syndrome.

#### Inspiration

As a group of people familiar with the history of Down syndrome and it's treatments, we recognize that we are still at the beginning of our journey to discover the full potential of individuals with Down syndrome. The star represents our collective reaching for a brighter future for all individuals with Down syndrome.



## Top 20 Volunteers

DSI would like to thank the following volunteers for their ongoing time and commitment to enhancing the lives of individuals with Down syndrome.

Angie Cain	258	Dee Sheda	170	Jessica Green	129	Jessica Green	129
Joe Meares	90	Ellen Kempksi	88	Joel Persinger	49	Jan Huffman	45
Patricia Finkley	32	Libby Sheda	24	Dr. Schreiner	20	Marty Mason	17
Rob Morgan	14	Morgan Sheda	11	Dominique Lewis	8	Mary Glowner	8
Vickie Hartman	8	Lyle Liechty	7	Katie Ceglio	5	Emily McMath	5

## Down Syndrome Indiana December, January, and February Contributions

Down Syndrome Indiana would like to recognize contributors whose gifts were received during December, January, and February. Down Syndrome Indiana is a 501(c)(3) not-for-profit organization. Contributions are deductible to the extent permitted by law. All funds received are appreciated and will be used to further the objectives of Down Syndrome Indiana.

### \$1000 - \$2500

Indiana Farm Bureau Insurance  
James Sammer  
Edvin Xhako  
Zink Family Foundations Inc

Lisa Ashby  
Joshua Click  
Cindy Cobb  
James and Susan Cumming  
James & Suauan Nicely  
Richard Darko  
Andy & Alicia Dillingham  
Katherine Ivcevich  
Cathy Kleifgen  
Nancy Lee-Careskey  
Juliet Roberts  
Debbie Skomp  
Spindletop Oil & Gas Co  
Janine Wilson  
John Vanderlaan  
Yessa Household

Laura Jean King  
Kelle Lindenberg  
Paula Meguiar  
Monsanto Fund  
Nelda Morton  
Anne Moss  
Jeanne Parker  
Karen Scimeca  
Rebecca Slover  
George Spaeth  
Mary Wolfe  
Ruth Wyn  
Morgan Zoeller

### \$100 - \$990

William Calvert  
Robert Decker  
Duke Realty Corporation  
Frankey's  
Vincent French  
Gardner's Wrecking Service  
Liberty Mutual /Give With Liberty  
Angela McDaniel  
Mary McQueen  
Monarch Beverage Charitable Foundation  
Martha Moore  
Sherri O'Keefe  
Lisa Pfeiffer  
Lesli Pringle  
Kate Rewers  
SIA Foundation Inc  
Smith Family  
Kathryn Taylor  
Nick and Barbara Tillema  
Ron Wolfe

### \$25.00 - \$49.99

Janet & Josh Arnold  
Edward & Elizabeth Bush  
Jane Conley  
Lisa Dillon  
Mildred Fausset  
Dottie Fleming  
Christine Frye  
Mildred Fausset  
Frye Family  
Kimberly Giesting  
Amy Harvey  
Don & Janice Jacklich

### \$1.00 - \$20.00

Allstate Giving Campaign  
Kim Easton  
Joanne Hester  
Ted &Carolynn Lester  
Gina Lovell  
Jean Otto  
Charlene Payne  
Marcia Pospychalla  
Jodi Rose  
S M Sigman  
Kate Steele  
Stefani Steiner  
Sarah Welty

### \$50.00 - \$100.00

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— This ad features the Sell family Kerry, Jen, Emily, Jessica, and Nora —

## DSI Wish List

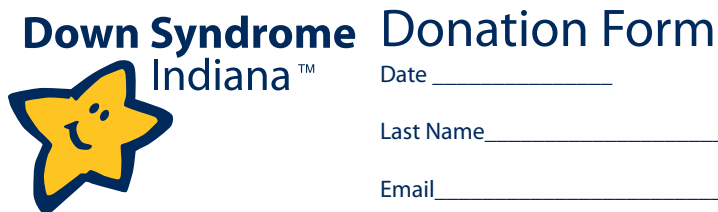
By donating items on this list that are gently used or no longer needed, Down Syndrome Indiana can provide families with items that they need, cut back on its administrative costs and make sure that more money is devoted directly to mission and programming. Thank you!

- |                          |                            |                      |
|--------------------------|----------------------------|----------------------|
| -Plastic storage totes   | -Dishes                    | -Button down pajamas |
| -Furniture               | -Hangers                   | -Bags                |
| -Infant/Toddler clothing | -Clothing Racks            | -HP 56 or 57 ink     |
| -Clothing hangers        | -Basic tool kit for office |                      |

-CVS gift cards, Speedway gift cards, or Walmart gift cards to be used for Helping Hands.

If you are interested in donating any of the above items, please contact the Down Syndrome Indiana office at 925-7617 or email Lisa at [volunteer@indianadsf.org](mailto:volunteer@indianadsf.org).

You can also drop the items off between the hours of 8:30am and 3pm on Monday thru Friday or during any Saturday volunteer workday at the DSI office.



Date \_\_\_\_\_

Last Name \_\_\_\_\_ First \_\_\_\_\_

Email \_\_\_\_\_ Preferred Phone \_\_\_\_\_

Agency Name (if applicable) \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_ Zip Code \_\_\_\_\_

Ethnicity: (Optional) \_\_\_\_\_ Gender (Please circle one) Male Female

Are you interested in volunteering for DSI? (Please circle one) Yes No

Relationship to an individual with Down syndrome: ( Please circle all that apply)

Parent Professional Grandparent Educator Self Advocate

Sibling No Relation Loved one of an individual who is now deceased Other

I would like to support Down Syndrome Indiana's mission to serve as a helpful resource providing information, support and activities that, combined or individually, promote growth and participation of people with Down syndrome in their communities. I would like to make the following contribution:

\_\_\_\_\_ \$ 25.00 \_\_\_\_\_ \$ 50.00 \_\_\_\_\_ \$75.00 \_\_\_\_\_ \$ 100.00 \_\_\_\_\_ \$250.00 \_\_\_\_\_ \$500.00 \_\_\_\_\_ \$ 1,000.00

\_\_\_\_\_ Other amount (Please write in amount): \_\_\_\_\_

Please place a check mark next to the method of payment below:

\_\_\_\_\_ Check (Make payable to the Down Syndrome Indiana and mail to: Down Syndrome Indiana, 3050 North Meridian Street, Indianapolis, IN 46208).

\_\_\_\_\_ Charge Card: Please fill in additional information:

\_\_\_\_\_ Visa \_\_\_\_\_ MasterCard \_\_\_\_\_ Other. Please write card type here: \_\_\_\_\_

Account #: \_\_\_\_\_ Expiration Date: \_\_\_\_\_

Authorized Signature: \_\_\_\_\_

Down Syndrome Indiana is a 501 ( c ) ( 3 ) not-for-profit organization. Contributions are deductible to the extent permitted by law. All funds received are appreciated and will be used to further the objectives of Down Syndrome Indiana. DSI's Federal Tax ID # is 35-1957015. Your contact information will be added to the mailing list promptly. You will receive a thank you letter and receipt in the mail.



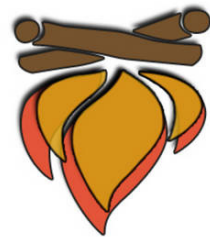
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Address Changes: Each issue of common bonds is sent via bulk mail. If you are have moved contact us as soon as possible. The newsletter is available in an electronic format. If you are interested in receiving common bonds by e-mail, please send your request to: [register@indianadsf.org](mailto:register@indianadsf.org).

**Camp Hi-Lite 2009**  
Camp Hi-Lite is a one week outdoor living experience for school aged and adolescent children who happen to have Down syndrome. It is held at Bradford Woods, just South of Indianapolis on a 2,500 acre parcel of land given to Indiana University in the 1930's. This year campers will attend June 14-19, 2009.  
D.A.D.S. helps to sponsor the camping opportunity. Applications for 2009 are due by April 15th, 2009. For more information or for a camp application, please contact Marsie Harrington [ringm@iupui.edu](mailto:ringm@iupui.edu) or by phone at 317-274-4264.



*Dedicated to enhancing the lives of individuals with Down syndrome...*



**common bonds**