



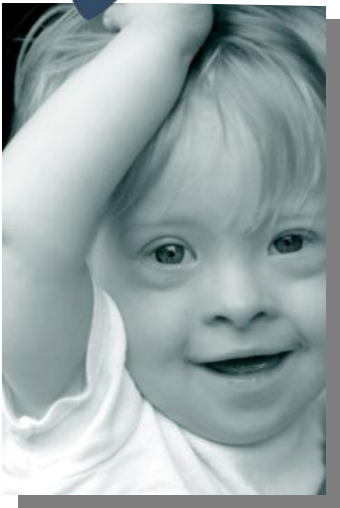
VOLUME 9, ISSUE 3

Down Syndrome
Indiana™



common bonds

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



Positive Attitudes About Ds

Three studies have just been published in the American Journal of Medical Genetics regarding attitudes of family members. Brian Skotko, Sue Levine and Rick Goldstein reported feedback from 2,044 parents/guardians, 822 brothers/sisters, and 284 people with Down syndrome around the country reported that Down syndrome is far more positive than many healthcare professionals describe. Following is a short list of results from the three studies:

- 99% of parent/guardians said they loved their child with Down syndrome;
- 94% of brothers/sisters expressed feeling of pride about their sibling;
- 99% of people with Down syndrome said they were happy with their lives."

American Academy of Pediatrics Updates Healthcare Guidelines

In July of this year, the American Academy of Pediatrics Committee on Genetics released updated health guidelines for individuals with Down syndrome. Entitled, "Health Supervision for Children with Down Syndrome", a full text version of the report is available here:

<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;107/2/442.pdf>

Local physician, Dr. Marilyn Bull of Riley Children's Hospital, (whom many of our families are familiar with and regard highly), served as the Chair of the Committee on Genetics to author the guidelines. Through its outreach program, DSI is working hard to get the updated guidelines into the hands of the medical professionals that will most benefit from them.



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About Down Syndrome Indiana

Mission: Down Syndrome Indiana Mission
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.

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.

Reprints: We invite others to reprint items from volunteer times. 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.

Statement of Policy and Disclaimer: *common bonds* is published by Down Syndrome Indiana. The policy of Down Syndrome Indiana or the news publication *common bonds* is not to endorse any medical, therapeutic, or educational alternatives. This newsletter is to provide information about current developments within the Down syndrome community.

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Lori Winkler

Meet the DSI Staff



Tim Borek
Self Advocate Coordinator, Part-time
Email: Tim@dsindiana.org
Phone: 925-7617

No Photo Available

Firany Briceno
Outreach Coordinator, Part-time
Email: firany@dsindiana.org
Phone: 925-7617



Stephanie Glowner
Member Services Coordinator
Email: stephanie@dsindiana.org
Phone: 925-7617



Lisa Wells
Executive Director
Email: lisa@dsindiana.org
Phone: 925-7617



Mike Wolinsky
Director of Resource Development
Email: mike@dsindiana.org
Phone: 925-7617



Rachel Wood
Event Coordinator
Email: rachel@dsindiana.org
Phone: 925-7617

New Website Calendar

To better assist the people we serve, we have revamped our website calendar for ease of use. It now features a text search box and pop-up listings for each day's events. We hope you will use this calendar more for all DSI-sponsored events such as self advocate activity nights, Moms' Night Out, DSI D.A.D.S meetings, and more. Add the News & Events page to your browser Favorites today!

<http://www.dsindiana.org/NewsEventsPublications.php>

An Adventure Fit for an Explorer by Andrew Ingram



Above: Andrew Ingram and Candy pause from their latest adventure to pose for a photo.

Below is a beautiful story by Andrew Ingram, a 13year old student at the International School about his friendship with a neighbor who has Down syndrome...

Thousands of babies around the world each year are born with Down syndrome. I am fortunate enough to live next to a very special, fun, and energetic person. She is a big part of my life and she has Down syndrome. Her name is Candy. I have known Candy for my entire thirteen years of life and she is a pleasure to be around. Ironically, we share the same birthday and she is actively plotting a celebration party that will consist of bowling and Subway sandwiches. While she is 53 years in chronologic age, she is ten at heart.

One of Candy's favorite pastimes during the summer is feeding the ducks in the local canal. Almost every evening Candy will go out with a bag of Wonder bread and throw little bits of bread in the canal so the ducks can eat them. I am often asked to join these little adventures, and I always choose to go if I am able. She is like a kid in a candy shop when she is doing something with our family, and considers interactions with me and my brother to be a special treat.

After secretly planning for nearly six months, Candy went on a little surprise trip to Chicago about a year ago. Nobody knew that she was going until we noticed she was missing, and we found a hidden note that said she had gone. It read, " Mom, Don't worry and don't call my brothers. I'll be back in three weeks". Candy had planned everything out very cleverly from the transportation to the hour her mom was taking her daily nap. We were all very worried but we soon discovered that she had gone to see her friend Betsy in Chicago. After two lengthy cab rides and an adventure fit for an explorer, Candy was home.

Another thing that Candy loves to do is go bowling on Saturday mornings. She is quite good at it too. My family and I have received many hysterical voice messages from Candy where she is arguing with her mother over the phone about whether she is going or not. We always take her to bowling when she asks. It is always a very fun and funny car ride.

Candy also shows great compassion and strength by taking care of her mother who is ninety. In fact, very recently she may very well have saved her mother's life after she had a stroke. She called my mother, who is a pediatrician, who then called an ambulance to come and help our weakened neighbor. All the while Candy was as calm as a lake in the morning and she then proceeded to enjoy watching her favorite team, The Colts, in their playoff game. Candy is a great neighbor with lots of great qualities including a patriot, a cheerleader, and a huge supporter of our families little league teams, but most of all she is a great friend.

***Candy is a great neighbor with lots of great qualities ...
but most of all, she is a great friend. -Andrew***



The goal of the coalition and the website is to begin to tear down the barriers that have excluded students with intellectual disabilities from the experiences of college. The coalition believes that individuals with an intellectual disability can and should have the opportunity to gain meaningful employment that includes a full-time career, a living wage and insurance benefits if they so choose. In fact, the Indiana Postsecondary Education Coalition envisions a world in which young adults with intellectual disabilities have the option of electing college as part of their planning as they transition from high school to the adult world. A college experience, which can include, academic, social and vocational components is really about providing opportunities to gain knowledge and skills that can change a life of dependence to one of independence and productive work!

New Website Encourages College as an Option



The Indiana Postsecondary Education Coalition recently launched a website to inspire families of young children with an intellectual disability to consider

college as an option available to their child when (s)he graduates high school. The website is : www.thinkcollegeindiana.org. Now, families, educators and employers have a resource that emphasizes the value of a college life experience for ALL..

College Prep Checklist

This checklist is for students of all ages who haven't attended college or trade school, and parents of students in elementary and secondary school. It includes a "to do" list, starting with elementary school, to help students prepare academically and financially for education beyond high school. Each section is split into subsections for students and parents, explaining what to do. It also has publications and other websites that might be useful to them. For more resources visit thinkcollege.net. . This information is also in [PDF](#) format.: <https://www.disability.gov/education/student-resources/preparing-for-college>.



Is College for you?

A 42- page publication, Is College for You? guides students and their parents through a variety of issues, including career goals, learning styles, types of colleges and programs, advocating for yourself, important timelines, paying for college, accommodations, survival tips, and more. Check it out here: <http://www.iidc.indiana.edu/index.php?pageId=64>





Save the Date!
Down Syndrome Indiana
Holiday Party 2011

December 10th, 2011
5:00 pm – 9:00 pm

Location:
The Atrium
3143 E. Thompson Road
Indianapolis, IN 46227



Bring a Gift – Down Syndrome Indiana asks that attendees bring the donation of an office supply item as your gift to us for our wonderful free celebration.

Please RSVP to
register@dsindiana.org
or by calling
317.925.7617
There will be gluten-free
options available.



Comments Parents Hear

"The state has not increased its funding for special education services, which means that providing the services you WANT for your child means we would have to cut into the regular education budget."



Recall the Law: Federal and state laws/regulations require that a free appropriate public education (FAPE) be provided to every student with a disability needing special education and related services. It has been made clear by hearing officers and courts that FAPE cannot be denied because of cost or funding to the school. When a parent's request is denied, the school must provide them with an explanation of the reasons for the denial in a prior written notice of refusal.

Response: Schools like businesses and families prioritize what they will spend funds on and how much they will budget. So it is a matter of prioritizing special ed and regular ed budgets & expenditures. When someone says that the budget for travel, supplies or attorneys cannot be reduced, they are setting those items as a higher priority than other areas.

Possible comments: "I am aware that state agencies and schools are dealing with budget cuts and limited funds to provide required services. After we have finished this meeting to provide my child the services that are needed and required to be provided, I am willing to meet with school staff to discuss prioritizing current funds."

"It's really a matter of prioritizing the money that the district does have, and for our conversation today, this issue isn't about money, this is about _____." (add issue)

"Let's not end the conversation about John's need because of money - maybe this will not cost as much as you think. Other schools have come up with innovative ways to meet this need." (i.e. donations from the school PTO, community contributions, non-profits, etc.)

(Reprinted with permission by Partners Resource Network www.partnerstx.org)

Research Opportunities

Be sure to check the "[Research Opportunities](#)" page on the National Down Syndrome Congress website to see if there are studies going on of interest to you and your family: http://www.ndscenter.org/?page_id=630.

Fly-in Soars to New Heights



*Left:
Melaina
Everton
Serves
As the
Grand
Marshall
for the
2011
Fly-in!*

*See you
on August
4th 2012!*

Zionsville, IN - If there is any doubt an airport can be a positive addition to a community just take a look at what Indianapolis Executive Airport has accomplished with five years of fundraising. For Down Syndrome Indiana alone \$56,626.00 have been raised with the addition of more than \$13,000.00 from this year's Open House/Fly-In. More than a thousand people attended the August 6th, 2011 event planned and hosted by Montgomery Aviation. "We are so proud of the volunteers, supporters and sponsors for helping make each year's event such a success," said Andrea Montgomery as the check was received by Lisa Wells, the Executive Director of Down Syndrome Indiana.

The 2012 Fly-in will be on August 4th!



*Above:
Andrea Montgomery, and Michelle DeRhoulac of Montgomery
Aviation present DSI with check from Fly-in . See
Article above for more information.*



DSI To Partner With Midwest Fashion Week "Midwest Fashion Week Spring 2012: Design for Change"

INDIANAPOLIS, November 15, 2011— After a successful Fall 2011 season, Midwest Fashion Week (MFW) is already looking forward to Spring 2012! The series of events are set to take place March 10-17, 2012 at various venues throughout Indianapolis. Next season will reflect the theme: *Design for Change*. MFW will bring high fashion and style to Indianapolis and highlight local, national and international designers with Midwest connections. In addition, MFW plans to collaborate with Down Syndrome Indiana (DSI), as well as, other special causes. The Spring 2011 season events, including the DSI Fashion Gala and Monday Night Fashion, raised over \$70,000 for the non-profit organization. Once again, the Indianapolis Colts organization will be partnering with MFW as Colts Vice President, Kalen Irsay, the youngest daughter of Colt's owner, Jim Irsay, will be the Spring 2012 Patron of Honor! For further information on Midwest Fashion Week or general inquiries, please visit www.MidwestFashionWeek.com .



MIDWEST FASHION WEEK

DESIGN FOR CHANGE : MARCH 10TH—17TH, 2012

Midwest Fashion Week

Sunday, March 11th, 2012

Children's Fashion Show

Bella Vita at Geist

11699 Fall Creek Road

Indianapolis, IN 46256

Monday, March 12th, 2012

Monday Night Fashion

Colts Pavilion

7001 W. 56th Street

Indianapolis, IN 46254

Saturday, March 17th, 2012

Fashion Show Gala

Sheraton Indianapolis

31 West Ohio Street

Indianapolis, IN 46204

SAVE THESE DATES!!!

10th Annual DSI DADS Golf Outing June 1st 2012

The 9th Annual DSI D.A.D.S. (Dads Appreciating Down Syndrome) Golf outing at Pebble Brook Golf Club was once again an incredible success! The morning teed off with a press conference with acclaimed Hoosier golf course designer Pete Dye and Hoosier scenic landscape photographer and author, Micheal Gurnell. Over 300 golfers turned out to enjoy a day of golf, food, door prizes and of course beer!

Thank you to all our golfers and sponsors who helped raise \$81,000 to provide educational and recreational opportunities for individuals with Down syndrome including supporting Camp Hi-Lite, special events throughout the year and monthly meetings. We are honored to continue our simple mission *to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome.*

Save the Date for the 10th Annual Golf Outing on Friday, June 1, 2012!!



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

- DSI DADS Mission



Above: Dr. Richard Schreiner, DSI Board President, presents a donation check to Mary Crevey of the Riley Children's Foundation in support of Camp Hi-Lite. **Below:** Campers from Camp Hi-Lite thank you for your support.



Jessica's Circle

A DAY TO CELEBRATE
A TIME TO SHARE
FAMILIES AND FRIENDS
GATHER FROM HERE AND
THERE

SUN THAT'S BRIGHT
HEARTS THAT ARE FULL
LOVE FROM PEOPLE THAT
SURROUND YOU.

A TIME OF GIVING
WHATEVER YOU CAN
STAND UP AND SPEAK OUT
AND SUPPORT DOWN
SYNDROME

MAKE A DIFFERENCE IF YOU
CAN
HELP DSI AND ALL THEIR
FRIENDS
COME TO WALK FOR A GOOD
CAUSE
THEN YOU GET A BIG
APPLAUSE!

*Jessica is an active leader,
motivational speaker, and self
advocate serving on the Board of
Directors for both Down
Syndrome Indiana and the
National Down Syndrome
Congress.*

*For more information about DSI
Self Advocates and the writings of
Jessica Green, please visit their
blog at:
<http://dsindiana.blogspot.com/>*



Buddy Walk[®] 2011 Surpasses Goal!



Dear Down Syndrome Indiana Family and Friends,

I'm not even sure where to begin. I was so overwhelmed to see all of the love and support of our Down Syndrome Indiana families and friends at Saturday's 14th annual Down Syndrome Indiana Buddy Walk[®]. We

had a record number of Buddy Walk[®] teams this year and more than 4,000 people attended the 14th annual Buddy Walk[®]!!! We also met and exceeded our goal of raising \$211,000 for programs that will benefit individuals with Down syndrome and their families!!!

A special thanks to our top Buddy Walk Team, "Buddy's Beauties"! Great job to this team and their hard efforts in raising \$15,681 in donations for the Buddy Walk[®]! For those of you that were able to take part in Saturday's Buddy Walk[®], I do hope you and your family enjoyed yourself. The day was truly a success and we couldn't have done it without each and every one of you. As always, thank you to all of our families, friends, volunteers, sponsors, and donors for your involvement and participation. Without each and every one of you, Down Syndrome Indiana would not be able to continue its positive impact in the lives of thousands of Hoosiers.

I had such a great experience and look forward to next year's Buddy Walk[®] on Saturday, October 13th, 2012!!! Thank you all!

Warmest Regards,

Rachel Wood
Down Syndrome Indiana Event Coordinator

Down Syndrome Indiana would like to thank Rachel Wood for her three years of service to Down Syndrome Indiana. November 18th served as her last day with the organization. Rachel has been a dynamic staff member to say the least. While she will be missed, she is wished the best of luck and continued success in her new endeavor as owner of Rachel Wood Photography. Congratulations Rachel!

A huge and heartfelt thank you to all of the 2011 Buddy Walk® Teams this year! You are:

Aaron's Army, Abbigale's Court, Abby's Angels, Abby's All Stars, Airtron, All 4 Ezra, Allie & the All Stars, Alli's Cats, Alli's Pals, Andrea Scott Team, Aniah's Amazing Angel, Anna's Army, Ashlyn's Rubies, Ashton's All Stars, Boo's Brigade, Brady's Bunch, Brakayla's Beautiful Bow Brigade, Broad Ripple Martial Arts, Bryce's Bunch, Buddy's Beauties, Caleb's Corner, Caleb's Crew, Cameron's Crew, Care Bears, Caroline's Crew!, Carter's Crew, Conley's Crew, DA BEARS, Dash with Nash, David's Brown Derbys, Days of Elijah, Dez, Double J, Dr. Chuck's Angels, Eli's Posse, Emily's Butterfly Empire, Emily's Entourage, Emily's Island Amigos, Emma Jean Beauty Queen, Emma's Ambassadors, Evelyn's Entourage, Greyson the Great, Hendricks Crew, HOBOS, Hollis Adams All Stars, Ian's Entourage, Jacob's Journey, Javon's Jewels, Jessica's Gems, Jillybean, Jon 10:9, Jordan's Pit Crew, Joshua Riley Montgomery, JP's

People, Justyn's J-Walkers, Karon's Buddies, Kasey's Krusaders, Katie's Crew, Katie's Krew, Katrin's Krew, Krazy for Karley, Kyle's Buddies, LADSO, LainaBug, Lauen's Dragons, Lauren's League, Lauren's Team, Levi's Guardian Angels, Lexi Lou's Who's,

Walkers, Miles 4 Mia, Morgan's Journey, Morgan's Miles, Morgan's Mouseketeers, Mr. Mason's Buddies, Noah's Ark Buddies, Our Hope, Peanut, Pinkalicious Pirates, Pirau's Platoon,



Team Copass, Team Daelini, Team Daniel, Team Evan G., Team Gracie, Team Hayden, Team Issi, Team J2, Team Jillian, Team Lindsinator, Team LL Cool J, Team Nutrition, Team Piper, Team Princess Skilah, Team Ryan, Team Tater Tot, Team Whit, Team Tomes, Team Winscott, Team Zacman, Team Timmy, Tessa Toodles, The Alliance of Alexis, The Awesome Ashley's, The Drew Crew, The Brody Bunch, The Mac Pac, The Shamrocks, Tiny Dancer, Thomas's Bieber Fever Team, T's Team, Travis, Ty's Guys, Victoria's Other Secret, Walking with Faythe, WestPoint Special Care Team, Wild About Will, Will Power, Will's Walkers, Woods Walkers, Zoe Says....
Again, our many thanks on behalf of DSI!

TOP 5 BUDDY WALK® TEAMS

2012

- Buddy's Beauties - \$15,681
- Team Jillian - \$ 9,206
- Abby's Angels - \$ 6,090
- Team Aurora - \$5,893
- Team Catalina Joyce - \$5,552

Linda's Loved Ones, Lincoln's Locomotives, Little Lauryn's League of Awesomeness, Little Monkey, Livi Lou's Dudes, Logan's Buddies, Lucy in the Sky with Diamonds, MaCayla's Merry Marchers, Maddie Dashers, Maison's Marchers, Marching for Manny, Marching with Matthew, Marissa and Friends, Marty's Raiders, Melodee's Notes, Michael's

Prince Evan's Buddies, RADIO IRISH, Raegan Renee, Reach for the Stars: Team Ava, Rocklin Rylan, Ryder's Racers, Schreiner's Buddies, Simeon's Sidekicks, Sophia's Stars, Spencer's Striders, Stinky Pete's Moose Patrol, Super Logan, Tanner's Team, T-Bomb, Team Aurora, Team Austin, Team Avery, Team Bravo, Team Carlisle Trio, Team Catalina Joyce,



**Down Syndrome
Indiana™**



2625 N Meridian Street, #49
Indianapolis, IN 46208
Phone: 317-925-7617, 888-989-9255
Email: info@dsindiana.org
Website: dsindiana.org

Down Syndrome Indiana Statement About Prenatal Testing

Down Syndrome Indiana Statement About Prenatal Testing

Down Syndrome Indiana believes it is consistent with our mission to assist the medical community in providing current and accurate information about Down syndrome to expectant parents that receive a diagnosis of Down syndrome and/or parents that have a child born with Down syndrome and receive a postnatal diagnosis*.

Studies have shown that some parents choose to continue a pregnancy over termination because of positive images and stories about people with Down syndrome. Studies have also shown that some parents choose to continue a pregnancy over termination because of conversations with parents of a child with Down syndrome.

What Down Syndrome Indiana is Doing to Help

As a local support group whose mission is to enhance the lives of individuals with Down syndrome, Down Syndrome Indiana's Outreach Program (<http://www.dsindiana.org/Outreach.php>) strives to build relationships with the medical community through positive interactions and encourages medical personnel to distribute up to date and accurate information about Down syndrome to the families they serve.

*(The Prenatally and Postnatally Diagnosed Conditions Awareness Act and the American College of Obstetrics and Gynecology (ACOG) Practice Bulletin No. 88 both call for the provision of up to date and current information about Down syndrome and referral to a support group when the diagnosis of Down syndrome is made)

(Adopted by the Down Syndrome Indiana Board of Directors on May 19, 2011)