Greetings, friends and family of Down Syndrome Indiana! Can you believe this will be our 14th annual Buddy Walk? Thanks to your dedication and hard work, the 13th annual Down Syndrome Indiana Buddy Walk was a huge success, raising $186,633.08, our highest amount raised to date!!!

Down Syndrome Indiana has grown immensely over the years and I am certain that growth will continue in 2011. The Buddy Walk was established in 1995 by the National Down Syndrome Society to promote acceptance and inclusion of people with Down syndrome. Down Syndrome Indiana is proud to be one of the first organizations to host a local Buddy Walk®, and we hope our tradition continues for another 14 + years. Let's make 2011 our largest walk with the greatest number of teams and team donations to date! We have a goal of 250 teams and 5,000 walkers, and we can't do it without your help! You can register teams now at our FirstGiving page located at www.firstgiving.com/dsindiana/Event/buddywalk2011. There you will be able to get things rolling when it comes to registering for this year’s walk as well as raising funds.

As always, I thank you for your continued participation. If this is your first Buddy Walk, I appreciate your joining the tradition. 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 look forward to seeing you at this year’s Buddy Walk on Saturday, October 8th, 2011. Should you have any questions, please do not hesitate to contact me. Email rachel@dsindiana.org or call 317.925.7617.

Sincerely,

Rachel Wood
Buddy Walk Coordinator
Down Syndrome Indiana

Top team from 2010 Buddy Walk, Team Catalina Joyce

What is the Buddy Walk?

The Buddy Walk is Down Syndrome Indiana’s premier fundraising event. Participants walk a 2.6-mile no-fee course along the canal in downtown Indianapolis beginning at Celebration Plaza in White River State Park. Not only does the walk help obtain funding for Down Syndrome Indiana’s programming and services, it also spreads Down syndrome awareness to the community. This year’s walk is scheduled for Saturday, October 8.
Dedicated to enhancing the lives of individuals with Down syndrome

About Down Syndrome Indiana

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.

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.

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.

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Meet the DSI Staff

Lisa Tokarz-Gutierrez
Executive Director

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Tim Borek
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Mike Wolinsky
Director of Resource Development

Rachel Wood
Outreach Coordinator

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DSI FACTS:
Founded in 1996
Six paid employees
Nine community groups
Ask the Expert

Q: How do I know if my child has sleep apnea?
A: Snoring and obstructive sleep apnea are both breathing disorders that occur during sleep due to narrowing or total closure of the airway. Snoring is a noise created by the partial closure of the airway, which may often be more problematic than the noise itself. However, consistent, loud, heavy snoring has been linked to medical disorders such as high blood pressure. Obstructive sleep apnea is a serious condition where the airway totally closes many times during the night and can significantly reduce oxygen levels in the body and disrupt sleep. In varying degrees, this can result in excessive daytime sleepiness, irregular heartbeat, high blood pressure, and occasionally heart attack and stroke.

Individuals who have Down syndrome have a number of risk factors that contribute to this challenge. Some of the anatomical structures of the face can be one contributing factor. Weight is another factor that can affect the flow of air through the airway, and Thyroid disease is another component that can contribute to the level of risk. According to a Journal of Sleep Medicine article (August 2009), children who have Down syndrome have a 30–50% prevalence, and adults have even more factors for sleep apnea.

How do you know if you have sleep apnea? A sleep physician needs to diagnose this, based on the results of an overnight sleep study (polysomnogram).

How do I treat sleep apnea? There are a few ways to improve your condition. A weight management program may be beneficial. Avoiding alcohol and tobacco is also helpful. Sleeping on your side can decrease the severity of the problem.

If it has been determined by a physician that a patient has sleep apnea, medical and dental treatments including Continuous Positive Airway Pressure (CPAP), oral appliance therapy (OAT), and upper-airway surgery may be helpful. If you think you or someone you care about may have sleep apnea, talk with a physician and/or dentist.

“Do not ignore [sleep apnea]. Sleep is good; proper sleep is GREAT!”
— Steve Green, DDS

SAVE THE DATE!

Summer Picnic

July 10, 2011 at Southeastway Park

— Steve Green, DDS of Team Green Dentistry located in Fishers, Indiana
"The Buddy Walk has three primary goals:

1. To promote acceptance and inclusion of people with Down syndrome.

2. To raise funds locally and nationally for education, research, and advocacy programs.

3. To enhance the position of the Down syndrome community, enabling us to positively influence local and national policy and practice.”

Why Walk?

The Buddy Walk® was established in 1995 by the National Down Syndrome Society to celebrate Down Syndrome Awareness Month in October and to promote acceptance and inclusion of people with Down syndrome. Today, the Buddy Walk program is supported nationally by NDSS and organized at the local level by parent support groups, schools and other organizations and individuals.

Over the past sixteen years, the Buddy Walk program has grown from 17 walks to nearly 300 expected in 2011 across the country and around the world. Last year alone, 285,000 people participated in a Buddy Walk! They raised more than $11.2 million to benefit local programs and services as well as the national advocacy initiatives that benefit all individuals with Down syndrome.

The Buddy Walk is a 2.6-mile no-fee walk in which anyone can participate without special training. It is a wonderful, heart-warming event that celebrates the many abilities and accomplishments of people with Down syndrome. Whether you have Down syndrome, know someone who does, or just want to show your support, come and join a Buddy Walk in your local community!

The Buddy Walk has three primary goals: 1. To promote acceptance and inclusion of people with Down syndrome. 2. To raise funds locally and nationally for education, research, and advocacy programs. 3. To enhance the position of the Down syndrome community, enabling us to positively influence local and national policy and practice.

Proceeds from the walk help fund Down Syndrome Indiana programs and services that help individuals with Down syndrome families.

Programs & Services

Down Syndrome Indiana offers a number of programs and services. Here are just a few of our highlights:

- New Parent Information & Resource Packets
- Support for research and advocacy
- Financial assistance for youth who attend Camp Hi-Lite
- Information and Educational Conferences
- Parent Support Groups
- Mom’s Night Out events
- Family Picnics
- Self Advocates meetings and social activities

For more information about Down Syndrome Indiana, visit [www.dsindiana.org](http://www.dsindiana.org).
Individual and Team Registration

Team registration for the Buddy Walk® is NOW AVAILABLE at www.firstgiving.com/dsindiana/Event/buddywalk2011. Click on the “Register Now” link. You can register your team or you can register as an individual walker. With this site, you can easily create your own fundraising page and reach out to others to ask for their support. It also has the feature of downloading addresses from several online and offline databases (Yahoo, AOL, Outlook, etc.). In addition, if you have a Facebook account, you can use our Facebook application to share your page on your profile.

Let’s make 2011 our largest walk with the greatest number of teams and team donations to date!!! Down Syndrome Indiana needs your support in keeping its programs going strong for 2012 and beyond! Please contact us directly at 317.925.7617 to pick up registration and donation forms. Additionally this information can be found in the Buddy Walk 2009 Special Edition of Common Bonds.

Go Team!
Create a team to support an individual with Down syndrome. Collect donations online or in person. The team that raises the most money will act as the Grand Marshall for the walk and have their team photo displayed on the cover of next year’s brochure. For every $50 a team earns, the captain receives an official Buddy Walk® t-shirt to distribute to team walkers at the Buddy Walk.

Donations
Your sponsors can process donations online through your individual or group page. This is a secure site that accepts most forms of credit/debit cards with Visa, MasterCard, AM EX, and Discover. There are tools to promote your team on by email, Facebook, blogs, and websites. We also accept checks and money orders when online donations are not possible. Please be sure to download a donation form from our Buddy Walk page at www.dsindiana.org/files/content/BWalkDonationForm.pdf.

Directions to Celebration Plaza

Address:
White River State Park
Celebration Plaza
801 West Washington Street
Indianapolis IN 46204-2734

From the North
Take I-65 south to exit 114 (Martin Luther King Jr./West Street) to Washington Street; turn west and continue to the first stoplight at Schumacher Way. Turn right at the light.

From the South
Take I-65 north to I-70 west to West Street (exit 79A); turn north on West Street/Missouri Street to Washington Street; turn west and continue to the first stoplight at Schumacher Way. Turn right at the light.

From the East
Take I-70 west to I-65 north to exit 114 (Martin Luther King Jr./West Street) to Washington Street; turn west and continue to the first stoplight at Schumacher Way. Turn right at the light.

From the West
Take I-70 east to West Street (exit 79A); turn north on West Street/Missouri Street to Washington Street; turn west and continue to the first stoplight at Schumacher Way. Turn right at the light.

Parking
Parking for a fee is available at the Indianapolis Zoo, in the lot across from Victory Field, in the underground garage at the Indiana State Museum, and at parking meters located on Blackford Street convenient to the Congressional Medal of Honor Memorial. Additional parking can be found in the garage located at the corner of Maryland and West Streets.
Recall the Law: In the IDEA regulations at 300.105, it says that assistive technology devices and services must be made available when needed. "On a case-by-case basis, the use of school-purchased assistive technology devices in a child's home or in other settings is required if the child's Individualized Education Plan (IEP) team determines that the child needs access to those devices in order to receive a free and appropriate education (FAPE)."

The Response: Parents can demand/request that the IEP team consider whether the student needs AT devices and services. The parent must build a case that something (devices or software) is needed based on school data and hopefully with support from some school staff. For example, if a student is having difficult reading, devices that read material to the student could help the student learn the content despite their reading disabilities/difficulties. Remember that now the emphasis is on students with disabilities learning the state’s general education academic achievement standards. The basis for this would be school data showing that the student is reading below grade level and the logic that the student can learn orally. It could also include the fact that the student is not passing the state assessment test. Also note that the regulations mention devices for the home. Parents can discuss the student’s difficulty in doing homework and the amount of time it takes. AT devices and software can also help address issues with writing, math, listening, and organizational skills.

DSI believes that assistive and adaptive technologies should be in reach of every student. This should be part of the natural environment in the classroom. Parents should not be forced to justify, in the case conference committee, the needs for assistive and adaptive technologies. The case conference committee should be free to focus on identifying the appropriate technologies and tools based on a meaningful assistive technology assessment that is performed by a professional skilled in the art. Further, the technology should align with the curriculum where appropriate and be part of the overall system approach to Universal Design for Learning (UDL).

Possible Comments: "My child could learn more of the curriculum and/or demonstrate what they have learned better using AT devices and software that are available."

"I am requesting an assistive technology evaluation to assess what devices and services would assist him in the areas of (list)."

"The data that we have discussed today show that she has needs in the following areas: (list). I am requesting (specific devices or an AT evaluation) to address these needs."

DSI Now Accepts Vehicle Donations

Down Syndrome Indiana is more than happy to accept your used vehicle donation as a means to financially support its mission to enhance the lives of individuals with Down syndrome. For more information, please contact Mike Wolinsky, Director of Resource Development at 317-925-7617 or email mike@dsindiana.org.
Postsecondary Education Article Available Online

Even though the majority of high school students with disabilities identify participation in postsecondary education as a goal for their adult lives, only about three out of ten have taken classes since completing high school (National Longitudinal Transition Study-2). And among those with the lowest rates of participation are students with intellectual disabilities. The article Impact: Feature Issue on Postsecondary Education and Students with Intellectual, Developmental and Other Disabilities explores what we know, and what we still need to know, about supporting increased participation of students with disabilities – especially those with intellectual disabilities – in postsecondary education, and why that participation is important. To download a copy of this article for free, visit http://ici.umn.edu/products/impact233.

Family Info Guide to Assistive Technology and Transition

This 50-page guide is aimed at providing families with the information they need to effectively prepare for and participate in periods of transition in their children's lives. Individuals may order one free copy of the guide. To request print copies, visit www.fctd.info/show/order_guides.

"On a case-by-case basis, the use of school-purchased assistive technology devices in a child's home or in other settings is required if the child's Individualized Education Plan (IEP) team determines that the child needs access to those devices in order to receive a free and appropriate education (FAPE)."

Special Needs Apps for Kids

SNApps4Kids is a community of parents, therapists, doctors, and teachers who share information on how we are using the iPad, iPhone and iPod Touch with children who have special needs. To learn more, visit http://snapps4kids.com/.
Sleep Apnea

I would like to tell you about something I have learned. I was always tired and sleepy during the day, so my parents took me to the doctor. My doctor ordered a sleep study to see why I was so tired during the day.

I went to have a sleep study and I found out that I have a certain type of sleep apnea. The doctor wanted me to work out three times a week to keep my weight down and be healthy. He also wanted me to start using a CPAP machine. Using the machine gave me anxiety so I was unable to use it.

So my dad made me a mouth guard. He calls it an oral appliance. I started using it and started feeling better and lost some weight.

I had another sleep study to see if the mouth guard was helping and the study showed it did. I still have a way to go to lose some weight. One thing I do every night is wear my mouth guard.

I recommend that if you are tired a lot, go to a sleep apnea doctor who also knows about Down syndrome.

— Jessica Green

Gluten-Free Recipe

Dilled Chicken & Rice Casserole

Ingredients

1 cup rice, uncooked
1 cup chopped celery (2 stalks)
½ cup chopped onion (1 medium)
½ cup chopped green bell pepper (¼ medium)
3 tablespoons margarine or butter
3 tablespoons potato starch flour
1 ½ teaspoon salt
1/8 teaspoon salt
1 ¾ cups milk
1 tablespoon dried parsley, crushed
1-3 teaspoons dried dill weed, crushed (to taste)
1 cup sour cream (or non-dairy sour cream substitute)
2 cups cubed cooked chicken (or turkey)
½ cup toasted, crushed gluten-free break crumbs (see note below)

Directions

1. Preheat oven to 350 degrees.
2. Cook rice according to package directions.
3. Meanwhile, in a large saucepan, cook the celery, onion, and bell pepper in the margarine until tender and the onions appear translucent.
4. Stir in potato starch flour, salt, and pepper (if used).
5. Add the milk all at once, stirring constantly until thickened and bubbly. Cook for 2 minutes more.
6. Stir in parsley and dill. Remove the pan from the heat and stir in the sour cream.
7. Stir in the rice and chicken.
8. Pour into a 1 ½ quart casserole dish. Top with the bread crumbs.
9. Bake uncovered at 350 degrees for 35 to 40 minutes, or until heated.

Makes six servings.

Note: To make the bread crumbs, toast day-old bread slices. Crumble the toasted pieces with your fingers or chop in a food processor to the desired size.

Dilled Chicken Noodle Casserole: Prepare as above, but substitute 2 cups of cooked gluten-free noodles for the rice.
Ist-Quarter Contributions

Helios ~$2500+
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Carole Thor
Dawn Welch
Ina and James Wilson
Shelia Yaney

Ina and James Wilson
Shelia Yaney
Book Review

Adults with Down Syndrome
(Brooks Publishing Company, 2006)

Siegfried M. Pueschel

People with Down syndrome are living longer, fuller lives than ever before, and Adults with Down Syndrome is a comprehensive book on the social, clinical, legal, and personal issues these individuals will navigate. Internationally recognized authority, Siegfried M. Pueschel blends contributions from respected professionals with insightful first-person essays by adults with Down syndrome themselves. Together, these experts give readers research-supported information and practical advice on key topics such as social relationships, medical and mental health issues, postsecondary education, sexuality, employment, recreation, and living arrangements.

An invaluable reference for families and a wide range of professionals — including educators, clinicians, direct support professionals, transition specialists, and employment specialists — this landmark volume will help readers support individuals with Down syndrome as they build healthy, satisfying, and independent lives.

Buddy Walk® Volunteers Needed

If anyone is interested in serving on the Buddy Walk® Committee, please contact Rachel Wood by email at rachel@dsindiana.org or by phone 317.925.7617 for more information!

If you are interested in volunteering on the day of the walk, please contact Rachel Wood by email at rachel@dsindiana.org or by phone 317.925.7617 for more information!
Comments That Parents Hear (continued)

The Remark: “We do not currently have a special education teacher on this campus. A general education teacher would not be able to meet your child’s needs in his/her classroom.”

Recall the Law: “Unless the Individualized Education Program (IEP) of a child with a disability requires some other arrangement, the child is educated in the school that he or she would attend if not disabled. A child with a disability is not removed from education in age-appropriate regular classrooms solely because of needed modifications in the general education curriculum.” 300.116(c)(c)

“Public agencies, therefore, must not make placement decisions based on a public agency’s needs or available resources, including budgetary considerations and the ability of the public agency to hire and recruit qualified staff.” Comment to 300.116.

The Reason: The Individuals with Disabilities Education Act (IDEA) emphasizes educating a student with a disability on their home campus. Schools can have centralized programs in special situations. If the situation is about hiring or funding for a teacher position, the student might have to be transported to another campus to receive special services. The Individualized Education Plan (IEP) could reflect that the student will return to the home campus when a teacher is hired.

The Response: “What services and supports can be provided to my child and the school staff that would make it possible for my child to attend our neighborhood school/home campus now?”

“Since some of the services will have to be provided at another location, which services can be provided her at our neighborhood school/home campus? It is important that my child be with her/his neighborhood peers and siblings whenever possible.”

“Since the issue is the lack of a special education teacher, let’s indicate on the paperwork that my child will return to this campus when a teacher is employed.”

The Remark: “We don’t use that method or curriculum at this school.”

Recall the Law: There is nothing in IDEA that requires an IEP to include specific instructional methods. However if the IEP team determines that specific methods are necessary for the child to receive FAPE (Free and Appropriate Public Education,) then those methods can be included in the IEP. IDEA and NCLB (No Child Left Behind) emphasize using research-based methods, but the comments to IDEA say, “there is nothing in the Act to suggest that the failure of a public agency to provide services based on peer-reviewed research would automatically result in a denial of FAPE.” comment to 34 300.320(a)(4)

The Reason: Parents, as part of the IEP team, have the right to request that certain instructional methods be used and included in the IEP.

The Response: “The lack of or limited progress that my child has made could indicate that this method is not the best one to be used for my child. What other methods have been or could be tried?”

“The curriculum I’m requesting has been researched and proven effective with learners like my child.”

“What are the objections or concerns about the method that I have suggested?”

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2011 Buddy Walk® Sponsorship Opportunities

For as little as $100, your business can be included among these Buddy Walk supporters:

- Beaty Construction
- BKD, LLP
- Carmel Pediatrics
- Cassidy Turley
- Fusion Alliance
- Lyle Foundation
- Midwest Orthotic & Technology Center
- National Bank of Indianapolis
- Pathways Photography
- Petroleum Traders Corporation
- Speech Pathology Services
- The Kroger Co.
- WestPoint Financial

For details, call Mike Wolinsky at (317) 925-7617 or e-mail him at mike@dsindiana.org.

SAVE THE DATE

Camp Hi-Lite

at Bradford Woods

July 31—August 5, 2011

Register online:
www.dsindiana.org/files/content/2011CampHi-LiteApplication.pdf