



Down Syndrome Association of Northeast Indiana  
1413 West Coliseum Blvd.  
Fort Wayne, IN 46808

NONPROFIT  
ORGANIZATION  
U.S. POSTAGE  
PAID  
FORT WAYNE, IN  
PERMIT NO. 1219

May 2006

## mark your calendar

### Self Advocate Bowling

Bowling every Tuesday at 7:00 pm at Wayne Recreation and every Wednesday at 6:30 pm at Westwood Lanes.

### May 31, 2006

#### IDSF Annual Meeting

Riley Auditorium. Featuring speaker Dr. William Cohen. (For more information, please see inside of newsletter.)

### July 21-23, 2006

#### THE 34th NDSC National Convention Marriott Marquis, Atlanta Georgia

Don't miss this chance to attend the nation's largest convention for people with Down syndrome, their families, friends and the professionals who work with them! Contact NDSC at [www.ndsccenter.org](http://www.ndsccenter.org).

### August 7-11, 2006

#### 2nd Red Cedar Camp for People with Down Syndrome

DSANI is once again partnering with AWS

and Camp Red Cedar to offer a one week camp specifically designed for people with Down syndrome, ages 6 and up. Contact Red Cedar at 637-3608 for more information.

### August 22-26, 2006

#### 9th World Down Syndrome Congress Vancouver, British Columbia, Canada

The NDSS is co-sponsoring this conference instead of conducting a U.S. national conference in 2006. The world congress is held every three years to provide leading edge, broad based information providing a balanced perspective on current issues of concern for people with Down syndrome, their families, the professionals who work with them and researchers. [www.wdsc2006.com](http://www.wdsc2006.com).

### October 7, 2006

#### DSANI Buddy Walk

10am at Foster Park, Old Mill Road. Registration at 9:30 am, walk begins at 10 am. Call DSANI at 471-9964

### Saturday, October 28, 2006

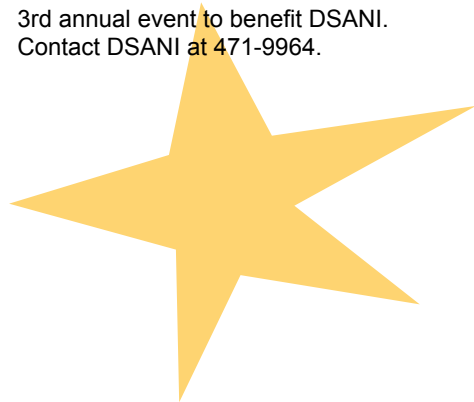
#### "Afraid to Look Down" IPFW

Told with unflinching honesty and humor, "Afraid to Look Down" is a play that explores the journey actor/playwright Cullen Douglas took in becoming a first-time father to his oldest son Gabriel- born with Down syndrome. [www.afraidtolookdown.com](http://www.afraidtolookdown.com).

### Wednesday, November 22, 2006

#### Auburn Moose Lodge Fundraiser

3rd annual event to benefit DSANI. Contact DSANI at 471-9964.



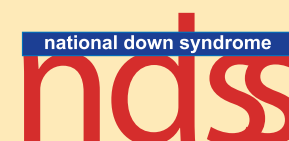
1413 Coliseum Blvd Fort Wayne, IN 46806  
260.471.9964 877.713.7264  
[www.dsani.org](http://www.dsani.org) [dsani4u@aol.com](mailto:dsani4u@aol.com)

*"The Down Syndrome Association of Northeast Indiana exists as an advocacy organization to enhance the lives of individuals with Down syndrome, provide information and support to families and professionals, and promote awareness and acceptance of individuals with Down syndrome within our community."*

#### DSANI Board of Directors

Senior Advisors.....Tom & Rita O'Neill  
President.....Julie Tutwiler  
Vice President.....Brenda Amburgey  
Secretary.....Marsha Scheitlin  
Treasurer.....Theresa Bickel  
Newsletter/Website.....Open Position  
Programs.....Karen O'Boyle  
Outreach.....Jessi Kamleiter  
Administrative.....Marilyn Miller  
Buddy Walk.....Jennifer Mihuc  
Self Advocate.....David Miller  
Self Advocate Coordinator.....Pat Nuffer

DSANI is an affiliate organization of the National Down Syndrome Society (NDSS) and the National Down Syndrome Congress (NDSC).



Education. Research. Advocacy

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666 Broadway New York, NY 10012  
800.221.4602  
[www.ndss.org](http://www.ndss.org) [info@ndss.org](mailto:info@ndss.org)



NDSC  
130 Center Dr. Suite 102  
Atlanta, GA 30338  
800.232.NDSC  
[www.ndsccenter.org](http://www.ndsccenter.org)  
[info@ndsccenter.org](mailto:info@ndsccenter.org)

## 2006 Buddy Walk



Hopefully you have marked your calendars and saved the day for the 2006 Buddy Walk because it is going to be a fun and exciting event with lots of great new activities for this year.

One exciting new addition will be the 2006 Buddy Walk t-shirt. Our main design this year will be created by our own John O'Boyle. John will create a one-of-a-kind design that will appear on the front of the t-shirt. You won't want to miss this chance to get a piece of DSANI Buddy Walk history.

We need your help to add all of the new ideas this year. If you or family or friends have a business that would like to help support Buddy Walk we are looking for sponsors as well as companies willing to provide a variety of prizes that we can use as incentives for team spirit, top fundraisers etc. If you can help, contact Jennifer Mihuc as soon as possible. Contact Jennifer at [misssslydia@aol.com](mailto:misssslydia@aol.com) regarding your ideas to help Buddy Walk.

Also, new this year – the DSANI School Challenge. We are looking for schools to help raise awareness of individuals with Down syndrome by using a variety of activities in the school. If you are interested in more information on the school challenge, please contact Challenge Coordinator, Jen Pickard today. Contact us at [pickfam4@msn.com](mailto:pickfam4@msn.com) to help with the School Challenge.

## DADS Golf Outing

Help support the mission of DADS and enjoy a great day of golf. Attend the 4th Annual DADS Golf Outing on June 9, 2006 at Pebble Creek Golf Course, Noblesville, IN. The events of the day will include 18 holes of golf, lunch, pre-golf activities and dinner and a raffle. Registration is just \$100 per person. One of the goals of DADS 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 for individuals with the mental and physical disabilities. For more information or to register, contact Scott Harding at [scottharding@fepco-inc.com](mailto:scottharding@fepco-inc.com) or 317-770-0260.

## Camp at Red Cedar



Come camp with us! Once again this year, DSANI and AWS will join together to offer a camp experience for children and young adults with Down syndrome.

Camp activities include swimming, fishing, hiking, horseback riding, boating, camp songs, arts & crafts and much more. Most importantly all activities are done in a safe and friendly environment since all counselors will be specially trained and low camper to staff ratios will be maintained. Cost is \$325 and DSANI will offer scholarships of \$150 to member families. Minimum age to participate is 6 years old. Contact Red Cedar today to reserve a space!

## Sunshine Baskets

Is your child with Down syndrome facing surgery or other hospitalization? Please let DSANI know so we can deliver a Sunshine Basket of goods to your home or hospital room. Baskets include items to make the hospital stay and recovery easier on both parents and child. Contact us at dsani4u@aol.com or 260-471-9964.

## Play Group

Join us for a play group for children with Down syndrome ages newborn to 6 and their parents. Play group will be held at the home of Jennifer Mihuc, 2605 Union Chapel Road, on Saturday, May 13 from Noon to 3 PM. Refreshments will be provided. Please RSVP to Jessi Kamleiter at jkamleiter@hotmail.com.

## IDSF Annual Meeting

Indiana Down Syndrome Foundation Annual Meeting

Wed., May 31, 2006 at the Riley Hospital Auditorium

This evening is intended for all individuals with Down syndrome, their families, caregivers, educators and healthcare professionals. The public is invited. Admission is free.

Babysitting will be provided; however, registration is required.

6:30pm Reception  
hosted by the IDSF Board of Directors

7:00pm President's Message & Financial Report

7:30pm Keynote address by William I. Cohen, MD

Reservations are requested. Please call IDSF, 1-800-989-9255.

About the speaker... Dr. William Cohen, professor of pediatrics and psychiatry at the University of Pittsburgh School of Medicine, is a nationally renowned Down syndrome expert. He is the developmental-behavioral pediatrician director at the Down Syndrome Center of Western Pennsylvania at Children's Hospital of Pittsburgh.

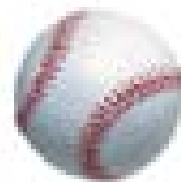
## Attention All Baseball Players...

This summer, the Huntington YMCA will again partner with the Miracle League to provide a baseball league for local children with special needs ages 3 to 19.

In the Miracle League, each player will be assisted according to his or her need, and will hit and score each inning, with the last batter each inning scoring a home run. There are two innings per game. This year's season will consist of eight games, all played inside the Huntington North High School Field House on Sundays beginning at 12:30 pm.

Cost to play is \$35.00. Each player will receive a Miracle League Baseball hat and shirt as their uniform.

Sign-ups begin Monday, April 24 and end very soon! To register your child, please call the Huntington YMCA at (260) 356-4200. With questions, please ask for Tim Allen, ext. 14.



## Abnormal Sleep Patterns Appear Common in Children with Down Syndrome

More than half of children with Down syndrome may have abnormal sleep patterns and obstructive sleep apnea syndrome, and parents may not be able to determine whether their children are among those with sleep difficulties, according to an article in the April issue of Archives of Otolaryngology – Head & Neck Surgery, one of the JAMA/Archives journals.

Obstructive sleep apnea (OSA) occurs when, during sleep, an individual's upper airway becomes blocked, resulting in a temporary cessation of breathing. OSA occurs in an estimated 30 to 60 percent of the Down syndrome (DS) population, according to background information in the article. Children with DS also are at greater risk for the development of obstructive sleep apnea syndrome (OSAS), a broader term for sleep abnormalities that includes complete and partial airway obstruction, chronic obstructive hypoventilation (inadequate ventilation with not enough air getting in the lungs) with hypercarbia (excess of carbon dioxide in the blood) and hypoxemia (lower than normal amount of oxygen in the blood).

Sally R. Shott, M.D., and colleagues from the Cincinnati Children's Hospital Medical Center, University of Cincinnati, Ohio, performed sleep studies on children with Down syndrome to determine the occurrence of OSAS. Fifty-six children with Down syndrome (ages four to 63 months, average age 42 months) completed overnight polysomnography (PSG), a test of sleep studies that monitors brain waves, breathing, stages of sleep and oxygen levels in the blood, among other variables. The children's parents also completed a survey about their child's sleep behaviors.

Thirty-two (57 percent) of the children had abnormal PSG results and evidence of obstructive sleep apnea syndrome. When the researchers included an elevated arousal index (ten or more disturbances in sleep per hour), 80 percent of the children had abnormal results. Rapid eye movement (REM) sleep should make up 25 to 30 percent of sleep time in children younger than five years old, and in this group, only nine children spent more than 25 percent of their sleep time

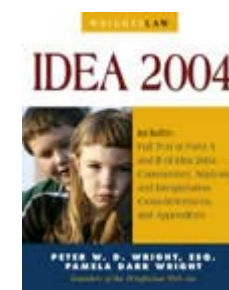
in REM. Of the 35 parents who completed surveys, 69 percent of them reported that their children had no sleep problems; however, among that 69 percent of children, 54 percent had abnormal study results. Thirty-six percent of the children of parents who reported sleep problems in their children had abnormal PSG results.

"Because of the high incidence of obstructive sleep apnea syndrome in young children with Down syndrome, and the poor correlation between parental impressions of sleep problems and PSG results, baseline PSG is recommended in all children with Down syndrome at age three to four years," the authors write.

Arch Otolaryngol Head Neck Surg. 2006; 132: 432 – 436. Information gathered from and reprinted with permission from Cincinnati Children's Hospital Medical Center, University of Cincinnati, Ohio.

Note: This study was funded partially by the Emily Ann Hayes Down Syndrome Research Fund.

## Book Review- Writslaw: IDEA 2004



This excellent reference book includes the full text of Part A (General Provisions) and Part B (Assistance for Education of All Children with Disabilities) of the Individuals with Disabilities Education Act (IDEA), along with commentary, cross-references, strategies, and tips.

This book starts out by introducing you to law, regulations, and caselaw. Next is an overview of IDEA 2004 that explains how the law is organized, highlights, and new requirements in IDEA 2004. This section is followed by the entire text of Part A & PART B. Appendices, a glossary of acronyms, abbreviations, and terms, along with a bibliographic list of resources complete this wonderful resource.

IDEA 2004 is confusing to most parents, educators, and even to some attorneys. This book will help you sort out answers to your questions. Anyone who has or works with children with disabilities needs to understand the law, and **should** read this book. Order your copy today at [www.wrightslaw.com](http://www.wrightslaw.com) or borrow the copy from the DSANI office.