



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

June 2006



DOWN SYNDROME ASSOCIATION OF NORTHEAST INDIANA

## Wizards Game



THIS IS FUN!

What a great day for a ball game! Over 100 DSANI members enjoyed a Wizards game and watched as our own David Miller threw out a pitch – way to go David!!



## 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.

July 8, 2006

### Black Pines Animal Park

Watch for more details.

July 17-21, 2006

### Swim Lessons

Contact Karen Boyle for more information.

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.

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 12, 2006

Join us for a trip to the Botanical Conservatory.

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.

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

October 21, 2006

### Halloween Bowling Party

Watch for more details soon on this annual fun event

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.

Wednesday, November 22, 2006

### Auburn Moose Lodge Fundraiser

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

December 9, 2006

### DSANI Holiday Party

Join us for the annual DSANI Holiday Party complete with a visit from Santa.



1413 Coliseum Blvd Fort Wayne, IN 46806  
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"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  
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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).

national down syndrome



Education. Research. Advocacy  
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## Raise Cash for DSANI by Surfing the Web

Now you can raise money for DSANI just by searching the Internet at GoodSearch.com.

You use GoodSearch.com like any other search engine - the site is powered by Yahoo! - but each time you do, money is generated for us. Here's how it works:

1. Go to www.goodsearch.com
2. Type DSANI into the "I support" box and click on "verify"
3. Since GoodSearch shares its advertising revenue with charities and schools, every time you search the web at GoodSearch, you'll be earning money for us.



GoodSearch also has a toolbar you can download from the homepage so that you can search right from the top of your browser.

You can keep track of our estimated earnings by clicking on "amount raised" once you designate us as your organization of choice. The more people who use the site, the more money we'll earn, so please spread the word!!

## Times Square Photo Contest

See yourself on the big screen! NDSS is now accepting photo submissions for the Times Square Video Photo Contest. The Times Square Video will air prior to the 2006 New York City Buddy Walk on September 17th (shown in New York City's Times Square on the NBC Astrovision screen by Panasonic). The video kicks off National Down Syndrome Awareness Month in

October and features photos of over 250 children, teens, and adults with Down syndrome working, playing, and learning with family and friends. To submit a photo online, please visit the Buddy Walk website at <http://www.buddywalk.org/> No more than three photos per family will be accepted. For more information, please contact Danielle Reddy at 212-763-4374 or [dreddy@ndss.org](mailto:dreddy@ndss.org).

## Rally at the State House

Due to IFSSA's Annual Plan Project in which service rates were cut for individuals served under Indiana's Medicaid Waiver program and the devastation it has caused to consumers, families and providers, a "Rally at the State House" is being formed. This Rally at the State House will be held on: June 19th @ 11:00am at the Indiana State House @ 200 W. Washington Street, Indianapolis, IN. West Side of the State House (side facing Senate Avenue)

This rally will allow any and all interested citizens to show their concerns over IFSSA's handling of the Medicaid Waiver program including the case management consolidation, the lack of needed services for safety and health, the

lack of emergent services, lack of needed services for families and their disabled relatives and the devastation to businesses and jobs. At this point confirmation of attendance has included consumers, advocacy groups, family members and providers from around the state. A petition will also be available for signature which will be presented that day to Governor Daniels. Media coverage will also be at the rally.

Please join this event and show your support for our developmentally disabled Hoosiers, their families and for the providers supporting these individuals. If you need more details, please contact: Bevaun Graves, Executive Director, Ascend, Inc. at [bgraves@ascendinc.biz](mailto:bgraves@ascendinc.biz)

## Special Care Sitter Training

Have you been trained as a babysitter? Are you seeking additional training in caring for children with disabilities? Are you a parent who has trouble finding a trusted babysitter who understands the needs of your child? Are you a community leader who is interested in being trained to teach babysitters how to baby-sit for children with disabilities? The Community Education and Child Advocacy

Department at Riley Hospital for Children will conduct trainings June 24 & September 23, 2006 in Indianapolis for those interested in becoming a Special Care Sitter or a Special Care Sitter Trainer. The course content includes education on disability awareness, introduction to medical and adaptive equipment, information on different disabilities, exposure to communication techniques, and

## Special Olympics

Recently several DSANI members took part in Special Olympics at Leo High School. We are proud of all of our athletes – great job!! Shown here are athletes, Jeffrey Minch and Griffin Tutwiler.



techniques that assist in adapting activities for children with different types of abilities. This course is not designed to teach how to care for children with complex health care needs, and the teenager is not taught special nursing skills. For more information call Christina Rogers at 317-278-7621 or send email to [cmrogers@iupui.edu](mailto:cmrogers@iupui.edu). PRE-REGISTRATION IS REQUIRED. Go to: [www.rileyhospital.org/kids1st](http://www.rileyhospital.org/kids1st)

## Editorial Thoughts on Being Tender

By Margaret W. Lewis

"On Being Tender" was originally printed in October 1983 in the NDSC's "Down Syndrome News". Margaret Lewis was the editor. The NDSC reprinted the article in 2001, and received a great deal of response from it. Originally printed in "Down Syndrome News", newsletter of the National Down Syndrome Congress, Volume 24, Number 2.

There is a dilemma, as an editor, in meeting the need of the public relations impact, of proving beyond the measure of a doubt that children and adults with Down syndrome have potential – that formerly inconceivable capacities are possible for people with Down syndrome.

The dilemma is that, in striking out with our best foot forward, we sometimes run the risk of kicking, quite cruelly, some parent whose cherished child will never go to high school, never give a public talk, perhaps not even speak at all.

Continually we hear talk of stories

of success, of tip-top achievements. Often there is humor and gentle acceptance of imperfections, but in each of us as parents there seems to emerge that insidious seed of wanting to have, as someone put it, the "best child with Down syndrome." Having conquered (we like to believe) the grief of not having the typical child we expected, we still play for the winner's circle.

And it is good to have high expectations. Good to take joy in the little triumphs, good to show a doubting public that our kids too are wunderkinds. But where is the line, where is the edge of tenderness that keeps us aware of the hurt of others? The great thing we as parents of children with Down syndrome share with one another is the vulnerability we each inherited when our particular child was born to us. The automatic humbling came to us every one, and out of it was created a kinship unlike any other but that pain can bring.

In the end, of course, it's a matter of individuality. The final joy is in the achievement, the communication – whatever level – of each child as

himself or herself. The final proof of our humanity is in the non-comparing love we can show for our children and for each other.

But, if chance has dealt you a "high functioning" kid, take a few minutes and role-play the part of the parent of a child who doesn't read, or count, or jabber hundreds of words. How do you insulate yourself from the "what did I do wrong?" feelings, the "maybe if I try harder..." feelings, the just plain jealous, wounded feelings that surge up over the triumphs of another child—particularly one close to your own child's age—and then the guilt feelings of knowing you should be taking unalloyed pleasure in the achievements of someone else's little genius.

We need to interact with one another as parents and encourage one another with reasonable expectations. Let us be sure that we are not reduced to bragging at the expense of someone else's dignity and despair. Our advocacy is for every single child born with Down syndrome, not just the cream of the crop!

## New Book Coming! You Can Help!



My greatest teachers have been adults with developmental disabilities--they're the true experts.

They've shared personal experiences of their lives with me--experiences from their childhoods and their lives today--and they've helped me become a better parent and a wiser human being. In turn, I've tried to share this wisdom with others in my presentations

and writings. But I know there's much more wisdom out there, and I'm collecting the personal stories of adults with developmental disabilities in a new book--a book that can help parents, educators, service providers, and others learn what's really important to children and adults with developmental disabilities! Download the Request for Stories (pdf) at [www.disabilityisnatural.com](http://www.disabilityisnatural.com), or write to me at [kathie@disabilityisnatural.com](mailto:kathie@disabilityisnatural.com) and request the appropriate version of the Request for Stories!

## Self-Advocate Group

Self advocate bowling is starting up for summer league-- Monday night at Georgetown Lanes-- this is a young adults typical summer league; Contact Pat Nuffer for more information.

Also the PALS group continues to meet – contact Frank Mikulski or Pat Nuffer for more information.