

2009 ANNUAL REPORT



Message from the President

As a nonprofit serving northeast Indiana, DSANI's mission continues to focus on support, education and advocacy on behalf of people with Down syndrome and their families. Our efforts in 2009 reflected that mission.

We improved our outreach efforts to parents receiving a diagnosis of Down syndrome by revamping our referral program. We now personally deliver Expectant and New Parent Packets and Gift Bags rather than relying on medical staff to do so and, as a result, are connecting with new families more quickly. Also in 2009, we continued offering support to both new parents as well as existing DSANI families by coordinating age-specific and all-member social programs with mutual benefit to participants.

We extended our tradition of hosting educational opportunities for families by partnering with several state-wide organizations, including the Indiana Department of Education. It was our privilege to co-host with the DOE a conference on Individualized Education Plans (IEPs) in April.

We advocated for people with Down syndrome and their families throughout the year by participating in several public awareness efforts such as the media coverage of the Soul Brothers, a well-known hip-hop dance group of local young men with Down syndrome, by participating in the efforts of the state Down Syndrome Governmental Affairs Committee and the regional Northeast Indiana Disability Advocacy Coalition.

Over the last few years, families have shared with me that what they want most for their sons and daughters with Down syndrome is for them to be accepted in their schools, in their workplaces and in the community at large. We share those goals as well as the concerns in achieving them.

With the assistance of a generous grant awarded in 2009 from the AWS Foundation, we will expand our outreach programs beyond our own families into the medical community and general public in our 11-county region. Projects funded by this program will include upgrading our information systems, partnering with the National Down Syndrome Society to promote the My Great Story public awareness campaign, and updating our promotional materials. The grant will enable us to distribute resource materials to physicians and hospitals throughout northeast Indiana to assist them in delivering a diagnosis of Down syndrome.

As we recap 2009, please join me in thanking several board members who served for the last 3 years or longer and who are now passing on the baton: Marilyn Miller; Dave Roeske; Jason Greenman; Missy Reuille; and Natalie Herron. Our families, our organization, and our community are immensely enriched for their efforts. I am thankful for the privilege to serve with them and to serve you.



Together we all can
make a difference!

Jenny
Bockerstette



Outreach

In 2009, DSANI's outreach efforts included updating our Expectant and New Parent Packets, changing to a referral program and delivering these resources personally by visiting families of newly diagnosed babies with Down syndrome. In addition to the well-organized and up-to-date packets

of materials, the new families received gift bags to welcome the baby. The gift bags contain assorted items, such as a baby's toy, the book Babies with Down Syndrome: A New Parents' Guide, and a children's book for siblings. Outreach coordinator Missy Reuille, and other volunteers, make home and/or hospital visits based on the needs and wishes of new parents. On-going contact is maintained via email and phone. Feedback given by new parents reveals this initial outreach effort is very valuable as families face uncharted territory following the birth or adoption of a child with Down syndrome. Outreach volunteers help parents connect with community services such as First Steps and Medicaid waiver. For more information on assisting with or connecting someone to DSANI Outreach programs, call Missy Reuille at 485-9898 or email her at mreuille2@comcast.net.



Programs



In addition to the many special-interest or age-specific activities that DSANI sponsored in 2009, a number of other programs met with great success. In February, DSANI hosted inspirational comedian Dan Kulp, who shared his experiences of growing up with five brothers and sisters with Down syndrome and his journey as a father of a son with Down syndrome whom he adopted from China. Disability advocate Kathie Snow spoke at our Annual Meeting in March and promoted inclusion of people with disabilities. In April, DSANI co-hosted with the Department of Education, InSource and other state organizations an IEP workshop at Summit Middle School. A picnic was held at

Buckner Park in June. DSANI families turned out in great numbers to enjoy a TinCaps game at the new stadium in August. In September, the 7th Annual Stewart Golf Scramble to benefit the Buddy Walk was held at McMillen Park. In addition, DSANI co-sponsored the IPFW Omnibus Lecture featuring Marlee Matlin and Henry Winkler. DSANI's programs, member photos and DSANI's 2009 Buddy Walk PSA were included in a pre-lecture video for attendees. The highlight of our year, our 11th Annual Buddy Walk, was held the first weekend in October and was our best Walk yet. In December, our programming ended with a bang with three holiday parties for our families.



Grandparents Group

The DSANI Grandparents Group offers a wonderful opportunity for grandparents to support family members and each other in a nurturing and caring environment. The group held three official meetings in 2009 and also hosted a picnic with their grandchildren. The grandparents assisted with the Buddy Walk

fundraiser in several ways, including driving the train and manning a table at the walk to share information with other grandparents of children with Down syndrome. Sharing together about the growth and progress of their grandchildren is a highlight of the group, says Jackie Geimer, co-coordinator with Nancy Reuille. Goals for 2010 include helping again with Buddy Walk and involving more grandparents. For more information on this group, call Jackie at 260-724-9186 or email her at Jackie.Geimer@Fleetwood.com; or call Nancy Reuille at 749-4224.

in 2009 was the hockey DADS night at the Memorial Coliseum. The relaxed atmosphere built camaraderie and enabled group members to encourage one another, said group coordinator Jason Greenman. The group's goal is to grow in numbers and offer more events of varying kinds. For more information, call or email the 2010 DADS co-coordinators Jeff Zinn at 432-3041 or jjinnaz@yahoo.com or Chris Fleischer at 338-2213 or chrisfleischer@comcast.net.



Infant-Toddler Playgroup

The DSANI Playgroup creates opportunities for infants and youngsters through kindergarten to play and socialize while their parents and siblings find support in a fun environment. The group meets monthly in homes, at the library, at parks or community pools. Dinner together is

frequently on the agenda. Attendance varies, with 15 to 20 families meeting regularly, up from six families when the group started in 2006, says Playgroup coordinator Stacey Foust. Memorable activities in 2009 include: the Halloween party; gymnastics classes; Kindermusik classes; indoor playtime at Indiana Tech's Andorfer Commons Recreation Center; and weekly pool parties at North Side Park. Occasionally a Dads' Night Out or Moms' Night Out are organized. Even when family schedules prevent regular attendance, parents email each other for encouragement and advice, with 56 families now on the group's email list. For more information, call Stacey at 485-1673 or email her at jsfoust@verizon.net.



DADS Group

Dads Appreciating Down Syndrome, or the DADS Group, saw growth in 2009, with 10 to 13 people attending special events that brought together dads in support of each other and building strong families. By sharing personal experiences

and information with one another, DADS participants realize they are not alone in this journey of fathering a child with Down syndrome. One highlight



Parent Network

In a move that strengthens DSANI's ability to advocate for children and adults with Down syndrome and their families, in 2009 the DSANI Parent Network folded into the Powerful Parent Advocacy (PPA) chapter of IPMG, which is the state-contracted company managing Medicaid waivers. Powerful Parent Advocacy meets at

6:30 p.m. every second Tuesday of the month at The League for the Blind and Disabled, 5821 S. Anthony Blvd., Fort Wayne. Longtime DSANI member Pat Nuffer continues to serve as a go-to person for parents who need assistance in maneuvering through and accessing services from various state programs for families whose children are aging out of the public school system. For more information, call or email Pat at 490-2908, patnuffer@gmail.com.



Friendship Club

The DSANI Friendship club is aimed at teens and young adults ages 12 to 21 who have Down syndrome. Now in its third year, the Friendship Club has grown from an average attendance of eight teens to upwards of 25 attending dances and other social activities.

Since its inception, the group has expanded to include teens with varying kinds of learning disabilities, as youths with Down syndrome develop friendships in school and the community. In 2009, seven events were held, most of them dances, and a highlight of the year was the first semi-formal dance held in May, with 35 in attendance. For more information on Friendship Club, call coordinator Kathy Meeks at 432-5278 or email her at KMMeeks@aol.com.



Self-Advocates Group

Individuals with Down syndrome who are 21 and older can find their niche in the Self-Advocates Group. With a current average attendance of 15, the group in 2009 enjoyed

attending a Mad Ants game, sponsoring a summer swim party and hosting a holiday party. Group co-coordinator Laura Lahrman hopes to increase attendance in 2010, with a specific goal of getting more women in attendance. Unlike many other social groups, males currently outnumber females in the Self-Advocates Group. The group is also looking at ways to become involved in service projects in the community. For information on joining the Self-Advocates Group or in helping organize an outing or if you are interested in providing a service project outlet for Self-Advocates, call or email Laura at 432-3359, LLSunny@verizon.net or co-coordinator Frank Mikulski at 484-3191, fmikulski50@verizon.net.



Buddy Club

Buddy Club offers social and recreational activities for children ages 6 to 12. Typically meeting every three months, the group enjoyed indoor playtimes at Indiana Tech's Andorfer Commons Recreation Center

with the DSANI Playgroup. In the spring of 2009, Buddy Club participants held a kite-flying day at Franke Park and in the fall took a tour of Salomon Farm, where wagon rides provided thrills. Marsha Scheitlin, 2009 Buddy Club coordinator, says there is great potential for the group to grow from its current average attendance of 15, which includes children and family members. The group is looking for new activities and community volunteers to host them. For more information, call or email the coordinator, Denise Pequignot at 723-6809, dpequignot@earthlink.net



THE TRAVELER

SUJEET DESAI

DO YOU HAVE A STORY?
TELL US AT NDSS.ORG/STORIES

dsani 260-471-9964
DOWN SYNDROME ASSOCIATION www.dsani.org
of Indiana

I play six instruments. I've visited eleven countries. I've traveled to thirty-two states, and been honored by The President of Singapore. I've met Oprah, been featured in TIME® magazine, and performed on the clarinet before 14,000 people. I have Down syndrome and this is my great story.



Camp Red Cedar

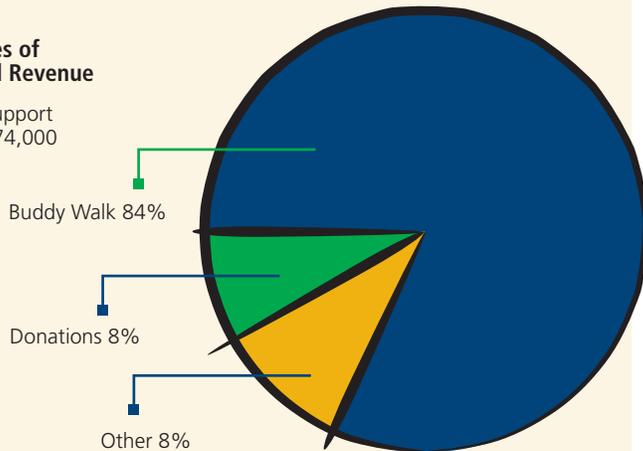
In 2009, a record 27 campers enjoyed DSANI Week at Camp Red Cedar. As always, the kids enjoyed horseback riding, swimming in the lake, pontoon rides, field games and camp crafts. This year, DSANI campers also had fun participating in a music and movement session led by instructors from Tumble X, a talent show they rehearsed for all week, and a carnival organized by the Junior High Youth Group at Covenant United Methodist Church. The Youth Group spent the week volunteering at Camp Red Cedar for their 2009 Mission Trip and created a video highlighting their experiences. Parents worked closely with the camp staff to refine daily activities and the evaluations by parents overwhelmingly showed the camp's positive impact on the children who attended.



Financial Overview

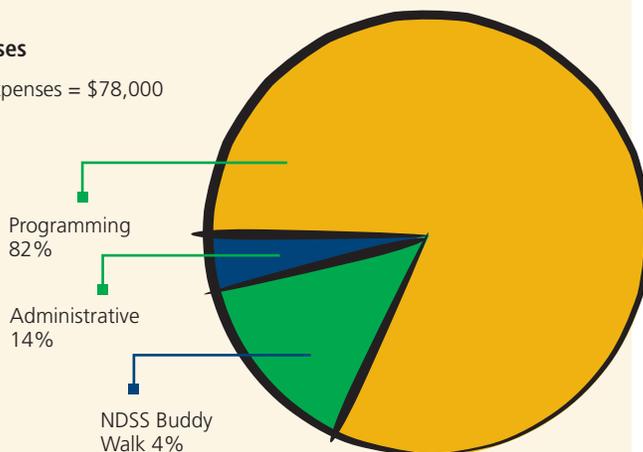
2009 Sources of Support and Revenue

2009 Total Support Revenue = \$74,000



2009 Expenses

2009 Total Expenses = \$78,000



Financial Position

	Dec. 31, 2009	Dec. 31, 2008
Total Assets	\$116,000	\$120,000
Total Liabilities	-\$3,200	-\$7,500
Net Assets	\$112,800	\$112,500

DSANI is a 501(c)(3) nonprofit organization as determined by the Internal Revenue Service.

Buddy Walk

The Buddy Walk is a day of celebration, an opportunity to promote acceptance and inclusion of people with Down syndrome, a time to catch up with old friends and, of course, a fundraising event for DSANI. Despite damp and chilly weather, over 1,100 people gathered at Foster Park for DSANI's 11th Annual Buddy Walk, raising over \$62,000 to support our programs and advocacy efforts. Highlights from the Walk include opening comments from Buddy Walk Grand Marshal and Komets Captain, Guy Dupuis, and Fort Wayne Mayor, Tom Henry, and the national anthem sung by Fort Wayne Councilman, Tom Didier. However, the hip hop dance by the Soul Brothers of Premiere Dance Studio had the crowd on its feet and cheering. Thank you to everyone who volunteered, collected donations and joined in the festivities. The money raised at the Buddy Walk supports our activities throughout the year.

2009-2010 Board Members

Jenny Bockerstette, President
 Dave Roeske, Vice President
 Lisa Teets, Treasurer
 Marilyn Miller, Secretary

Natalie Herron, Buddy Walk
 Nicole Dupuis, Public Relations
 Missy Reuille, Outreach
 Brandi Buck, Programs
 Sue Ehinger, Programs
 Frank Mikulski, Self-Advocates
 Laura Lahrman, Self-Advocates

Sheryl Sternal, Self-Advocates
 Brian Hedrick, Web Site
 Jason Greenman, DADS
 Tom O'Neill, Senior Advisor
 Rita O'Neill, Senior Advisor

Staff:
 Kimberly McCoy, Office Manager

DSANI Award Recipients



Sue Peoples

Matt Day



Patricia E. Bauer



Aaron Ott

Indiana's News Center



The DSANI Awards recognize those individuals or organizations who, consistent with our mission, have made a significant contribution to the Down syndrome community locally.

SUE PEOPLES Sue Peoples is the proud mother of four children, including her youngest son, Michael, 18, who has Down syndrome. Sue is a tireless advocate who in the past 13 years has dedicated her career as an educator to understanding how children with Down syndrome learn and to reducing the academic hardships encountered by children with Down syndrome and their educators. She is the author of *Stars of Success: Understanding How Children with Down Syndrome and other Developmental Delays Learn*. Approved by the National Down Syndrome Society, the book provides proven and effective instructional techniques for parents and professionals. Sue has been a featured speaker on educating children with Down syndrome at numerous conferences, including those sponsored by the National Down Syndrome Society and National Down Syndrome Congress, and has been extremely generous with her time and support of DSANI member families in the educational journey of their children.

MATT DAY For almost all of the past 11 Buddy Walks, Matt Day of Day Creative Solutions has been one of DSANI's most dependable volunteers, dedicating not only his time but his talent as well. Year after year, Matt's photography has captured and preserved our families, our children, and the spirit of the Buddy Walk. He is always well prepared, arrives early, stays late, and never expects anything in return. We are thankful for his time, his talent, and all he has graciously contributed to the Down syndrome community.

PATRICIA E. BAUER As a respected and nationally recognized journalist and the mother of a young adult with disabilities, Pat Bauer has written numerous op-ed articles on disability issues. Her articles have appeared in the Washington Post, the New York Times and other publications, and she recently wrote the foreword to Kathryn Lynard Soper's book: *The Year My Son and I Were Born: A Story of Down Syndrome, Motherhood, and Self-Discovery*. In addition, she maintains an invaluable resource for individuals and families of those with disabilities through her web site at www.patriciaebauer.com, an award-winning website that compiles news and commentary on current disability issues from the mainstream media. Pat also speaks at national conferences and to local groups, encouraging organizations and families to advocate for people with disabilities.

AARON OTT For several years, Aaron Ott has volunteered at the Buddy Walk helping other self-advocates distribute T-shirts. He is one of the hardest workers and his positive attitude is always appreciated. Aaron graduated from Homestead High School in 2003 and has continued to support the football and basketball teams since then, sometimes leading the team to the field or court, and informally keeping stats. His other activities include working at Arby's, volunteering at Lutheran Hospital, bowling (with a 124 average), supporting the Colts and Packers, and dancing with as many girls as possible at weddings. Aaron Ott promotes a positive image of a self-advocate in the Fort Wayne community.

INDIANA'S NEWS CENTER Indiana's News Center has been an exceptional supporter of DSANI's mission to promote awareness in Northeast Indiana and were instrumental in promoting the 2009 Buddy Walk. When approached about the possibility of airing pre-walk Public Service Announcements, Jim Turcovsky's response was both timely and accommodating. Producer, Al Crain created a local Buddy Walk PSA spotlighting DSANI member and Comet Captain, Guy Dupuis and son, Matthew. After an unsuccessful first attempt at taping, Mr. Crain volunteered to spend yet another morning with Dupuis and son to polish the commercial. Maureen Mespell and Corinne Rose were also exceedingly helpful in promoting the walk. More recently, INC has also agreed to partner with DSANI in promoting a campaign during Disabilities Awareness Month called My Great Story. This campaign will highlight the abilities of people with Down syndrome. Indiana's News Center has been an enthusiastic and refreshing organization to work with and is greatly appreciated by the Down syndrome community.

Down Syndrome Association of Northeast Indiana

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



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The mission of the Down Syndrome Association of Northeast Indiana is to enhance the lives of people affected by Down syndrome, advocate on their behalf, provide information and support to families and professionals, and promote acceptance and inclusion of people with Down syndrome in northeast Indiana.