

2010 annual REPORT



DSani
DOWN SYNDROME ASSOCIATION
of Northeast Indiana

"It's not our disabilities,
but our abilities that count."
-Chris Burke

Board Letter

The Board of Directors for the Down Syndrome Association of Northeast Indiana would like to take this opportunity to share some exciting information regarding our organization over the last year. As members of DSANI's Board of Directors, we believe that expressing our values and conducting our business in accordance with our Mission is an important part of maintaining the confidence and trust of the community we serve. The DSANI mission remains the same, 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. In accordance with our mission statement, the Board of Directors has been working hard to offer programming designed to reflect our mission of support, education and advocacy. Over the last year our efforts resulted in two trainings, "Handwriting without Tears" & "Reading Made Easy for Learners with Down Syndrome." In addition we participated in the first annual Disability Expo in Fort Wayne and co-hosted writer Emily Pearle Kingsley who spoke about raising a child with special needs. We also hosted our annual Buddy Walk and continued to sponsor several social programs.

Recognizing that the life blood of a non-profit is the strength of its volunteers, DSANI's Board of Directors is launching a new effort to recruit dedicated individuals who can help us realize the potential of the DSANI mission statement. Currently the DSANI Board of Directors is re-organizing board positions to include more committee-based responsibilities. We are announcing a new initiative designed to recruit and train the resource we need the most – volunteers. We believe that it is important that we use our volunteers' time and energy more efficiently. If you are interested in volunteering, please visit our Website at dsani.org and fill out the volunteer form to let us know your interests and talents.

Together, with the help of our volunteers, the Board of Directors believes the best of DSANI still lies ahead. Together we can work to accomplish a brighter future for individuals with Down syndrome and their families.

Sincerely,

DSANI Board of Directors

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

DSANI
DOWN SYNDROME ASSOCIATION
OF NORTHEAST INDIANA
260-471-9964
WWW.DSANI.ORG

NDSS
NATIONAL DOWN SYNDROME SOCIETY

MY GREAT STORY

SUJEET DESAI
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.

My Great Story Publicity Campaign Spreads Awareness Throughout Northeast Indiana

DSANI, in partnership with the National Down Syndrome Society (NDSS), throughout 2010 promoted the My Great Story (MGS) campaign in northeast Indiana with Public Service Announcements (PSA), print ads and through the internet. In August, DSANI was highlighted in an NDSS's webinar on national and affiliate partnership success with this campaign.

We were proud to boast that over \$5,000 of airtime was donated by Indiana's News Center during the month of March for the My Great Story public service announcements and for PSAs placed in Fort Wayne Newspapers' online home page at www.fortwayne.com. The PSA's ran on the home page of FortWayne.com 859 times during one month. We had My Great Story billboard advertising at four central sites in Fort Wayne. Additionally, the News-Sentinel and Journal Gazette ran ads that equate to 525,000 impressions. Fort Wayne Parenting and Fort Wayne Magazine, subsidiaries of Fort Wayne Newspapers, also ran My Great Story ads, respectively, on March 20 and March 26, 2010, reaching an estimated 68,000 readers with each ad. DSANI also sent press releases to 20 print and broadcast media outlets in 11 northeast Indiana counties.

Stories generated included the following:

- *Living It Up: Local adults with Down syndrome have big dreams*
By Jaclyn Youhana, the Journal Gazette; published: March 13, 2010
- *Mother deals with Down syndrome diagnosis*
By Amy Oberlin, the Herald Republican in Angola; published March 28, 2010
- *Down Syndrome highlighted in awareness campaign*
Staff Reports for KPCnews.com in northeast Indiana; published March 5, 2010

My Great Stories can be posted at www.dsani.org under Our Great Stories or through the NDSS Website at www.ndss.org/. The My Great Story PSA, featuring John McGinley, Meredith Viera, and Nancy O'Dell, can also be viewed at both of these Websites.



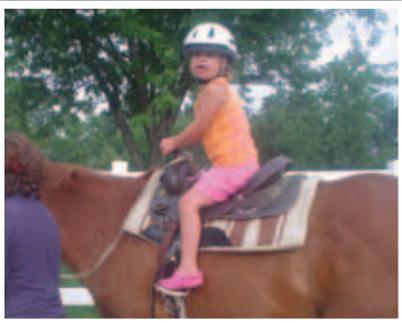
Camp Red Cedar

DSANI and Camp Red Cedar provided again in 2010 a summer day camp opportunity for children and youths with Down syndrome. The week of July 12-16, 34 children and youths, ages 6 through 21, attended Camp Red Cedar. The camp offers therapeutic horseback riding, crafts, swimming, tumbling and hiking activities. The week's highlight is always a talent show where all age groups and counselors participate in skits and dance performances for friends and families. Campers practice for the performance throughout the week.

This special week provides a one-to-one camper-counselor ratio for children ages 6 to 10 and a three-to-one ratio for those ages 11 to 21. DSANI provides scholarships to children and youths with Down syndrome, which offsets the registration fees for a full week of day camp. Campers make lasting friendships, learn independence and new skills and store up wonderful memories for a lifetime.



This group photograph of the 2010 campers was taken just before the annual Talent Show, something campers, their families and staff look forward to.



Sydney Pequignot enjoyed daily horseback riding.



Jacob Roeske, left, and his counselor, Nate, take a quick break from camp activities to pose for a picture.



Joe Bockerstette, far left, and Jenny Bockerstette, far right, were honored by DSANI in June 2010 with a farewell party and with the Tim and Rita O'Neill Award for their many years of work with DSANI. In center, from left is Deb Gavette, a founding member of DSANI along with the Bockerstettes, and Rita O'Neill.

Bockerstettes Leave City and Lasting Legacy for DSANI

In July DSANI board members, founders and long-time friends of the organization gathered to bid farewell to Joe and Jenny Bockerstette, who moved to Phoenix, Arizona. The Bockerstette's helped found DSANI 11 years ago. Jenny is DSANI's immediate past president and Joe served as president of the board for several years and is the immediate past board chairman of the National Down Syndrome Society based in New York.

While northeast Indiana has lost two of the strongest advocates for individuals with Down syndrome and their families, Arizona has gained their talents and leadership skills.

During the farewell dinner, many people shared memories of the impact Joe and Jenny had on them personally as well as the organization. Joe and Jenny were, for many families, the first people to visit them in the hospital or in their homes following the birth of a baby with Down syndrome. DSANI board member and self-advocate Sheryl Sternal's reading of the heartfelt letter she wrote about the Bockerstettes left not a dry eye in the room.

Joe and Jenny were presented the Tom and Rita O'Neill Award for distinguished excellence in promoting acceptance and inclusion of people with Down syndrome in northeast Indiana and for dedication to enhancing the lives of families affected by Down syndrome.



Sheryl Sternal read a beautiful tribute to the Bockerstettes that left no dry eyes.



Knights of Columbus member John Murray DSANI interim-Pres. Lisa Teets

Knights of Columbus

Every year the Knights of Columbus Indiana State Council invites DSANI to participate in their annual Tootsie Roll Drive. This fundraiser benefits organizations who support people with disabilities. This year they presented DSANI with a check for \$1,019.

Programs



DSANI Programs Had Great Participation in 2010: DSANI's Program Committee hosted several annual events in 2010 as well as a new and exciting Mom's Night Out for all DSANI members:

- On March 5, 2010, DSANI hosted its first Mad Ants group outing. There were 103 tickets requested for this event, and Valarie Hoffman, a self advocate, threw in the air the ceremonial jump ball to start off the game! The younger children also had a blast at this event, interacting with the players on the team and enjoying the high-five tunnels at the start of the game.
- On April 16, 2010, DSANI hosted a Mom's Night Out at Naked Clay Café. This event was for all DSANI moms; 20 members attended, and everyone enjoyed choosing a pottery item to paint such as a mug, mirror or coaster.
- DSANI in 2010 hosted two of the organization's favorite outings: the Fort Wayne Children's Zoo and a TinCaps game; 38 families (95 adults and 63 children) enjoyed the new African Safari at the Zoo.
- One of DSANI's most talked-about events was the annual Holiday Party for children ages 12 and under and their families; 81 adults and 85 children patiently awaited Santa's arrival. Despite a near-blizzard, all of our DSANI families and volunteers -- Girl Scout troops from St. Vincent's Catholic School -- made it through the heavy snows and were able to enjoy food, games and presents and have their photos taken with Santa.

Self Advocate Activities

- The DSANI self-advocate group for DSANI members ages 21 and older, enjoyed several new activities in 2010:
- In April they attended a semi-formal dance hosted by the Friendship club. A wonderful dinner, great dancing, and live entertainment made for an evening enjoyed by all.
- In June, a small group attended the Beatles Tribute concert at the Foellinger Outdoor Theatre. The music brought out some great dance moves from a few of our members!



DSANI member and self advocate, Michael Lahrman, 22, on right, and his brother, Dan, enjoy a cool dip in the pool at the Self Advocate's Summer Swim Party in August. The Self Advocates enjoy planning their own parties and activities.

The annual summer swim party was a big hit as the group enjoyed their own version of water polo followed by a cookout and more swimming. The year was topped off with our annual Self Advocate Holiday Party at Andorfer Commons. Bad weather was on the menu that day, but most of the group were still able to come for bowling, Wii challenges, pool, air hockey, ping pong and, of course, lots of more good food.

A goal for the Self Advocate Group was to bring in more educational and community service opportunities. In September the Red Cross presented a workshop on personal safety. Attendees learned how to use fire extinguishers and were then able to practice their new skills hands-on. The evening also covered a wide range of topics that gave our self advocates the tools they need to be safe, whether they live away from home or are spending time alone at home. The evening was filled with great questions and answers. A dinner of pizza and soda was included. Our plans for community service projects will be expanded into 2011.

For questions and more information about the Self Advocates Group, call Laura Lahrman at 260-494-7772, or email her at LLSunny@frontier.com. We welcome new ideas and activity and service project suggestions. DSANI looks forward to seeing this group grow in numbers and in activities relevant to their desires and needs.



Fall pumpkin-picking

Buddy Club Equals Fun

Buddy Club is for children ages 6 to 12. The year was filled with many fun activities. Among the highlights:

- Spring kite flying,
- Picnics in the park
- The fall pumpkin-picking
- Joining other DSANI groups for outings and activities.

Contact Denise Pequignot at 260-723-6809 or by email at DPequignot@earthlink.net for

more information on the Buddy Club. We need volunteers from the community who would like to help organize a Buddy Club event, help sponsor an outing or even host an activity. The friendship and traditions shared by Buddy Club members build lasting relationships.

Friendship Club Activities

The 2010 Friendship Club activities included:

- A Valentine's Dance
- St. Patrick's Dance
- Family Indoor Luau
- Semi-formal Dinner Dance
- Back-to-School Pizza Party
- Halloween Dance;
- Holiday Party



Bethany Jewel made a beautiful Snow White at the Friendship Club's costume party.

The Friendship Club, which is for DSANI members ages 12 to 21, averaged 25 to 30 in attendance at 2010 activities. Socialization among peers at any age is enriching to the quality of our lives, and it is evident DANCING is one of the group's favorite activities! Sharing things in common, whether that is the ups and downs of school life, how to make new friends, tips on the latest fashions or make-up or a discussion about sports, Friendship Club's name personify the heart of this group. Club coordinator Kathy Meeks can be reached by email at kmmEEKS@aol.com or by phone at (260) 432-5278.



William Rentfrow



Alayna Zinn

Infant-Kindergarten Playgroup

*Giggles and tears, lots of noise to the ears
Little clapping hands and grown-up cheering fans
Santa's big lap, even sometimes a nap
Babies crawling along, parents playing a song
Children's smiley faces and untied shoe laces
Not a dull, quiet time or getting kids in a line
Parents reading books, kids' inquiring looks
Trucks and baby dolls, boo-boos from some falls
Then hugs and kisses for little misters and misses
Parents sharing together of the challenges to weather
That's the DSANI playgroup, where parents get the scoop
While children dance and sing, unaware they have this thing
It's called Down syndrome, but they're not alone
'Cause DSANI is there and we all do care.*

The Infant-Kindergarten Playgroup is a warm, welcoming atmosphere for new parents of children born with Down syndrome. In 2010, the Playgroup met monthly at parks, Andorfer Commons at Indiana Tech or at DSANI members' homes. DSANI parents often say it is through other Playgroup parents that they learn which medical providers have experience with and knowledge about Down syndrome and the special needs their children have. Parents discuss potty-training, language and motor development, eating problems and a host of other issues that only another parent with a child with Down syndrome truly understands.

For information on the group, on upcoming activities or how you can become involved as a parent or community volunteer, call or email Stacey Foust at 485-1673 or fouststj@gmail.com.

DADS Group Hosts Golf Tournament

The DADS Group (Dads Appreciating Down syndrome) exists to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome. By sharing personal experiences and information with one another, DADS participants realize that they are not alone in their journey of fathering a child with Down syndrome.

In 2010 the DADS group became responsible for organizing the annual DSANI/Steve Stewart golf event. On August 14th, 71 golfers participated in the event hosted at Deer Track golf course north of Fort Wayne. We look forward to growing this event in the future and offering more quality events to DSANI DADS. For more information please contact Jeff Zinn at jzinnaz@yahoo.com or Chris Fleischer at chrisfleischer@comcast.net.





2011 Star Award Recipients

The DSANI Star Awards are given annually to individuals or organizations that have had a positive impact on the people in northeast Indiana with Down syndrome and their families.



Lutheran Health Network, One Lucky Guitar and Lodge Design In 2010, One Lucky Guitar and Lodge Design worked with Lutheran Health Network as its advertising campaign shifted in a new direction that involved real patients telling real stories. On the Web, in print, over the radio waves, and on television, patients from each

of LHN's hospitals talked about their experiences with the network. Gone was the era of actors. The marketing direction speaks to the authentic, meaningful relationships that LHN's caregivers and hospitals establish with their patient families and has provided a deeper emotional connection with the audience.

Mindy and Chris Fleisher, who have had three babies born at the Dupont Hospital Birthplace, were chosen by Lutheran Health Network (LHN) and One Lucky Guitar and Lodge Design to share their unique experiences at Dupont Hospital. While the 30-second TV commercial focused on Gavin, the Fleisher's youngest child, who was born premature, Matt Kelly and Jason Roemer, co-creative directors of the new marketing project for LHN, gained new awareness, understanding and acceptance of those affected by Down syndrome. Matt Kelly and Jason Roemer said what drew them most to the Fleischer family was their strength, focus and positivity.

"The imagery and film of Raina, Tristan, who has Down syndrome, and Gavin playing together, and the pride in their parents' eyes, truly conveyed the amazingly beautiful experience of being a parent better than we would have ever been able to achieve with actors, actresses and catchy jingles. They were (and are) perfect," Kelly and Roemer wrote about the experience.



Michael Remus Michael Remus has been a general education teacher, special education teacher, school principal, college instructor, special education director for a school district and the special education director for the State of Kansas. Michael is also the parent of four children, two who have disabilities. Currently he is director of Special Education for Deer Valley Unified School District in Phoenix, Arizona. Most of his professional career has been in the classroom and in training parents and educators on how special

education works. He has worked in six educational systems with varying numbers of students, schools and geographic areas, guiding them through the challenges of systems change. He continues to consult with school districts and parent groups across the United States, provides individual assistance and training to parents and educators and serves as a speaker upon request. Michael is co-author of seven books for parents on how special education works, two training curricula based on his books, two effective practice manuals on special education for schools, a toolkit with the administrative tools needed to make inclusive education successful and a "Disability Awareness Activity Packet" for teachers.

Michael is also involved in the advocacy movement as a parent having been the national Arc president, a member of the President's Committee on Intellectual Disabilities and many parent organizations as well as professional organizations in the field of education. Michael is passionate about building school communities that embrace all students.



Susan James Kylie Bigham has been extremely blessed to have Mrs. Susan James as her special education preschool teacher for the last three years at Cedar Canyon Elementary, her mother, Stacie Bigham said in the nomination letter she wrote about her daughter's teacher. Susan James has been teaching special education in Northwest Allen County Schools for the past 17 years and is retiring at the end of this school year to pursue some of her own dreams. A 36-year

Fort Wayne resident, Susan also taught eight years in Fort Wayne Community Schools. Stacie Bigham said this of Susan: "Mrs. James is an amazing teacher who has more dedication and passion for children with special needs than anyone I have ever met. She has so much patience when it comes to teaching these children. Even her co-workers have said she has a way of getting children to accomplish things that they never would have thought possible. She has been an active supporter of DSANI and is always attending conferences or taking advantage of learning opportunities that DSANI provides to further her knowledge and abilities to work with children with Down syndrome. She has spent countless hours coming up with amazing ways to teach children and help them learn in a fun and exciting way. She has spent many classroom hours giving our children BIG praises for the "little" things that to most people go unnoticed. I will forever be grateful to Mrs. James for playing such a huge part in my daughter's life and development. I know she will always have a special place in Kylie's heart as well."



M & S Steel Corp For several years, M & S Steel Corporation has supported the various programs DSANI provides through major corporate sponsorship of the annual Buddy Walk. This sponsorship has made a considerable impact by serving as a benchmark for community support in DSANI's largest annual fundraising and awareness event. Walter Fuller, the president of

M & S Steel Corp, has demonstrated a sincere commitment to individuals with Down syndrome and their families and is graciously responsive with his support. Through the financial support of M & S Steel, DSANI has been able to provide more outreach services to families with a new baby diagnosed with Down syndrome, to provide education and support programs for parents, teachers, social workers and medical and mental health providers and to ensure advocacy for those affected by Down syndrome continues in northeast Indiana. DSANI is greatly appreciative of the generosity of Walter Fuller and M & S Steel.



Ashley Ely Ashley is a self advocate who fills her days helping others. Ashley volunteers at her church, her hometown elementary school and at Parkview Home Health & Hospice. Her warm heart, loving spirit, and friendly personality are admired by all the people whose lives she enriches every day. Helping others comes naturally to Ashley. It's just part of who she is, said DSANI member Laura Lahrman, who nominated the Woodlan High School grad for the Star Award. "Ashley

gives back to her community with such energy and pride, modeling to others the true joy to be found in the acts of kindness to others. Ashley is a shining example to her peers, and I believe she deserves to be recognized for the wonderful young woman that she is," Lahrman said in her nomination.

DSANI Thanks AWS Foundation

Over the past year DSANI has undertaken a public awareness campaign supported by the AWS Foundation to increase acceptance and inclusion of people with Down syndrome in northeast Indiana. Components of this campaign include:

- The updating of the DSANI brochure and newsletter and new marketing displays for events and conference use -- We have proudly made use of these displays at DSANI events, community outreach programs such as student volunteer expos and school presentations, and the regional events such as the disABILITIES Expo at the Memorial Coliseum in April and in November at the 20th Anniversary Celebration of the American with Disabilities Act (ADA) held at the Allen County Library Main Branch in downtown Fort Wayne.
- Planning and procurement of an integrated Website and contact/member database system – Review of various donor and member database software has been completed and evaluated to meet growing communication needs for members and community members. This new database software will work with a new Website to provide easier access to information relating to DSANI and Down syndrome issues locally and nationally. The Board of Directors is currently in the approval stage of this project's execution and budget.
- Medical professional outreach mailing – This initiative is near completion with the distribution of resources on the continuum of care provided by medical professionals in northeast Indiana who care for people with Down syndrome. Information also includes materials designed to assist a physician in delivering a diagnosis of Down syndrome to parents and the Healthcare Guidelines for

Individuals with Down Syndrome: 1999 Revision, edited by the Down Syndrome Medical Interest Group (a national affiliation of health-care providers specializing in caring for individuals with Down syndrome). A current database listing of physicians (OB-GYNs, pediatricians and rural family practitioners), including hospital contacts, has been compiled with over 100 resource packets already mailed and nearly 70 more packets that will be mailed by April 2011. Some physician's offices are now requesting more information be made available for patient use. DSANI will continue to communicate with these medical professionals in a variety of ways in the future.

DSANI is grateful for the gracious financial support by the AWS Foundation in continuing our mission and support through these important initiatives.

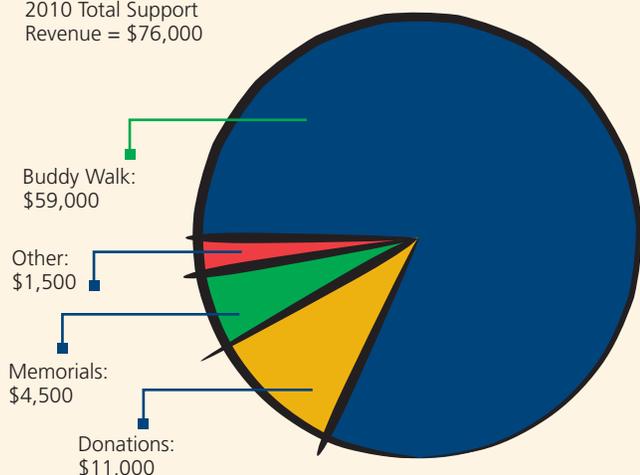
The AWS grant has also supported regional promotion of the national My Great Story campaign (see the inside front cover for info on My Great Story).

The mission of the AWS Foundation is to help children and adults with disabilities live as independently as possible, be included in society and function at their maximum potential. The Foundation also sponsors the Fantasy of Lights holiday display at Franke Park open yearly from Thanksgiving through Dec. 31. More information about the AWS Foundation is available at www.awsfoundation.org.

Financial Overview

2010 Sources of Support and Revenue

2010 Total Support Revenue = \$76,000

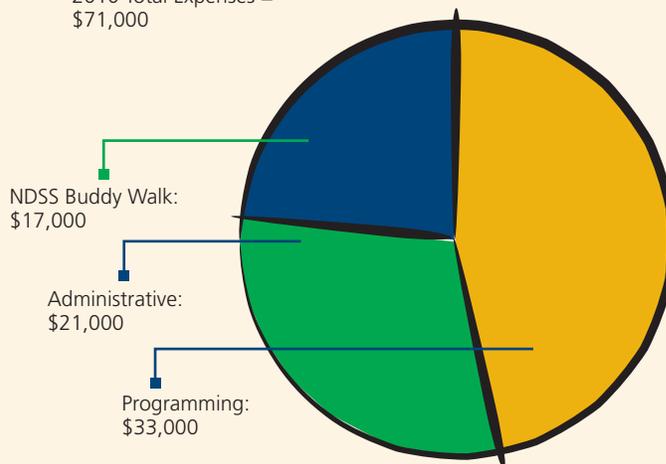


Financial Position

	Dec. 31, 2010	Dec. 31, 2009
Total Assets	\$128,000	\$116,000
Total Liabilities	-\$3,200	-\$3,200
Net Assets	\$124,800	\$112,500

2010 Expenses

2010 Total Expenses = \$71,000



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



Advocacy

DSANI Director of Administration Kimberly McCoy, in February 2010 attended the inaugural Buddy Walk on Washington hosted by the National Down Syndrome Society. McCoy joined Down syndrome organization representatives from across the country who participated in a half-day legislative training session followed by a full day of meetings on Capitol Hill with local and state lawmakers. They discussed pivotal issues relating to Down syndrome, including current legislation under review such as IDEA and the Kennedy-Brownback Act and research allocation funding.

On Oct. 1, 2010, the Northeast Indiana Disability Advocacy Coalition, of which DSANI is a member, hosted a candidate's forum for the 3rd Congressional District Candidates and state General Assembly candidates. The event was held at Abundant Life Church in Fort Wayne.

DSANI's participation in the Northeast Indiana Disability Advocacy Coalition (NEIDAC) supported community advocacy initiatives through monthly meetings of regional coalition members. NEIDAC's mission is to be a common voice and to advocate for equal opportunities on behalf of the disability community. Among 2010 events: nonpartisan candidate forums; voter registration drives; educational and self-improvement grants; hosting the April 2010 Abilities Abound Reception with Emily Pearl Kingsley; and, in collaboration with the City of Fort Wayne Metropolitan Human Relations Commission, the "Focus on Ability" event in November celebrating the 20th Anniversary of the Americans with Disabilities Act. Other events in which DSANI participated included: the disABILITIES Expo in April and the Brown Mackie College Career and Volunteer Fair.

On the state level, DSANI continues participation as a member of the Indiana Government Advocacy Committee via monthly teleconference meetings. This committee collaborates on advocacy and public awareness initiatives regionally and statewide while seeking to build private and public partnerships to create positive changes in public policy.



Students at Blackhawk Middle School in December chose DSANI as their charity of choice for an annual school fundraiser project.

Blackhawk Donation

On Dec. 17, DSANI members Steve and Sue Ehinger and their daughter Grace and DSANI Interim Board President Lisa Teets attended the Blackhawk Middle School holiday program. DSANI was presented with a check in the amount of \$6,733.58 raised through the efforts of the Student Council and the school population!! The Student Council held dances, Jar Wars contests and sold "Puppy Chow" and donuts during special movie times.

We were overwhelmed by their efforts and generous spirit!!

A special thank you goes to Stacey Hays, Grace Ehinger's aunt, who nominated DSANI to be considered for this cause and to Steve Ehinger and Guy Dupuis who spoke to the Student council to talk about our organization and the community we represent. The guys made a great impression because the students vote to decide who will receive the money.

We have several families who are members of DSANI and have children at Blackhawk.



Buddy Walk 2010

Buddy Walk 2010 raised over \$62,000, with more than 1,100 walkers starting their trek in Foster Park with umbrellas. The rainclouds cleared just in time for completion of the walk and for participants to enjoy great food, music, games and prizes made possible by the many generous businesses and merchants in the community that gave more than \$10,000 in in-kind donations. The top three teams raising the most money included: Friends of Tristan; Matthew's Mates; and Walking Gracefully.

Mark the date for Buddy Walk 2011, which is Oct. 1. Come join us! Buddy Walk is DSANI's largest fundraiser and makes possible the education, outreach and advocacy services provided children and adults with Down syndrome and their families.



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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