



2009 ANNUAL REPORT

Our mission is to enhance the quality of life for all individuals with Down syndrome by providing resources and support to those individuals, their families, professionals and the community.

LETTER FROM THE PRESIDENT

2009 has been a year of exciting growth and change for ODSPN.

- Five of the original board members of ODSPN completed their terms of service. I am grateful to Carena Burtzel, Lori Eyth, Katie Schiefen, Erica Seipold and Kim Stoneburner for their service to our families, especially since we weren't quite sure what we were doing in the beginning, other than we knew we wanted to reach families.
- We hired our first part-time employee. Anne Mancini came on board in March 2009 and has been a valuable member of ODSPN, managing our communications needs, responding to requests from our families, and working on the behind-the-scenes jobs that make our events successful.
- Three new Board members have begun receiving information as their terms of office will begin in January 2010. I welcome Rob Church (Fundraising), Jen Shannon (Parent Outreach) and Roberta Tonjes (Medical Outreach). I know that they look forward to hearing from our families about events and activities.
- We received grants from the Hawks Foundation, Ralston Open Golf Tournament, DMSi Software, the Oliver and Ferrol Barklage Foundation, and the Metro Omaha Medical Society Foundation to begin our Expectant Parents Program. We are in the process of printing and putting together the plans to send this information to the medical community so that physicians and nurses will know what to say when speaking to expectant parents. We also published an Expectant Parents Guide. We debuted these publications at our presentation to UNMC Department of OB/GYN in November 2009 with the assistance of Emily Kean and Roberta Tonjes.
- I am always amazed at what a casual conversation can lead for our members. One of our members was talking to her Yoga teacher about trying to find a dance instructor for our teens and adults and her instructor said she might be interested, and that is how the Hip Hop Dance classes started. Another member said that she was interested in starting a Culturally Diverse group and that is in the process of happening. Two of our grandparents said that they were interested in speaking with other Grandparents, and that group also began.
- I am amazed on a daily basis of what our group has been able to accomplish. We have partnered with a number of other disability groups to co-sponsors events, sponsored tables for our membership at fund raising events for other disability organizations, and continue to meet the needs of our families- which is providing information, support, and training to all families- no matter how old their child.
- Thank you for the donations we received from individuals in honor or in memory of a person with Down syndrome. These thoughtful contributions are a wonderful way to support our mission.
- Thank you to everyone who utilizes their company's Matching Gift Program. That program resulted in over \$3,000 in added revenue in 2009.

As I look back on the 10th year of ODSPN and look forward to the 11th year, I am eager to see what growth and change will take place in 2010. I have, over the years, learned to expect great things both for and from our membership. Our second decade is sure to be just as exciting as our first!

Sincerely,

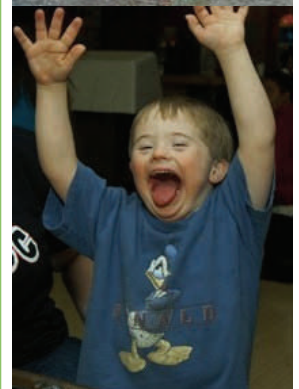
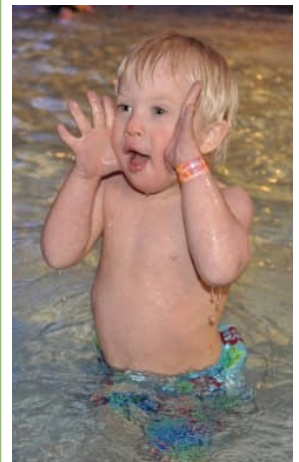
Mary P. Mc Hale

President

2009 Annual Report

Table of Contents

Letter from the President	1
Advocacy	2
Community Outreach	2
Events & Seminars	3
Buddy Walk	3
Board Members	3
Financial Overview	4





ADVOCACY

2009 was another active year for ODSPN. On a national level, Congress appropriated funds for the Kennedy-Brownback Bill, a bill that requires all physicians when delivering the news that a child will be born with Down syndrome, to present updated information, along with offering families the opportunity to talk to another family or affiliate group about what it is like to have a child with Down syndrome. ODSPN, however, didn't wait for the funding to be approved and for the government program to begin. We actively sought out foundations for funding sources, and were fortunate that ODSPN received initial funding to begin the program. In November, ODSPN presented its Expectant Parents Guide, Physicians Guide, and Nurses Guide to the UNMC Department of OB/GYN Grand Rounds. We have begun the process of providing resources for the medical community and will continue in the years ahead.



Washington, D.C. was the destination for two ODSPN Board members, Mary Mc Hale and Katie Schiefen, who participated in "A Day On The Hill." Mary and Katie met with Congressman Lee Terry, Senator Mike Johanns, and a representative from Senator Ben Nelson's office to discuss issues for individuals with Down syndrome. It was a successful day and over 300 affiliate leaders and self advocates across the country participated in this day, along with a 2-day session for leaders in the Down syndrome community.

ODSPN partnered with The ARC of Omaha to host a Legislative Policy Forum in November. The partnership with The Rose Theatre continued with scholarships provided to over 15 individuals with Down syndrome to attend acting classes.

The Down Syndrome Specialist (DSS) program continued to evolve, with over 22 school districts naming a DSS (or two) for their district. ODSPN hosted a breakfast in



January, and a movie night in partnership with Filmstreams, "Including Samuel." A copy of this movie was then given to all DSSs for use in their districts.

ODSPN also held a Transition Seminar for parents who had children transitioning into either kindergarten or middle school. It was well received by parents and will become an annual event.

The Special Educator award was given to Faith Keim, a Special Education pre-school teacher at Standing Bear Elementary. Faith was nominated by Tracy and Casey Campin.

ODSPN celebrated World Down Syndrome Awareness Day on March 20th at Barnes & Noble with a Pajama Rama Story Time.

ODSPN also sent over 75 gift cards to educators for National Inclusive Schools Week to celebrate those teachers who promote inclusion in their classrooms.

COMMUNITY OUTREACH

A new group, the Grandparents Group, started in 2009, by some grandparents who wanted to discuss and share with other grandparents. ODSPN is glad to be a part of this.

The Down Syndrome Super Moms group also began as a way for moms to get together. It continues to get bigger and bigger.

D.A.D.S. continues to grow and expand.

D.A.D.S. has partnered with Special Olympics with their Young Athletes program. This program is for children with disabilities ages 2 – 8. This





program, and some of our ODSPN children, were honored at the annual Special Olympics breakfast in February and also starred in the Opening Ceremonies for the Special Olympics Spring Games in May. D.A.D.S. continues to have activities and sessions for Dads and their families.

Presentations about personal experiences with having a child with Down syndrome were given to students at UNO, Metro Community College, Creighton University, and UNMC Department of OB/GYN. ODSPN also participated in the UNO Community Engagement Day for the 2nd year. ODSPN presented at Nurses Research Day at Methodist Hospital and also to Early Head Start Teachers.

ODSPN presented two New Parent Orientations for those families who have a child age two and under.

ODSPN began sending Happy Birthday gift cards to our membership. This has also been well received and we have received some delightful Thank You cards from our members.

ODSPN joined the digital age with a presence on Facebook and a message board for our members.

STRATEGIC PLANNING

The ODSPN Board's 3rd Annual Strategic Planning session was held in August, 2009 and incorporated valuable feedback from the membership surveys and focus groups.

EVENTS & SEMINARS

Special Events continue to be an important part of ODSPN for its membership. SkateDaze, bowling, swimming, Labor Day Parade, movie afternoons, and Parents Night Out continue to be widely attended by our membership. Some new events that were held this year included a Royals game, a day at the Omaha Children's

Museum, a pumpkin party, Putt-Putt golf, a night at CocoKeys, and an afternoon at the Body Shop. Over 1,200 of our members and their families have attended events that were held this past year.

Seminars continue to be important for our families. ODSPN partnered with ESU#3 to have Paula Kluth, Inclusion Specialist, present two seminars—one for parents and one for professionals.



ODSPN also continued surveying the membership for events and activities that hold interest for our families.

BUDDY WALK

The 2009 Buddy Walk continued ODSPN's partnership with UNO. New chairperson Allison Machamer and her committee continued the reputation that ODSPN has for its annual Buddy Walk—a fun, activities-filled event for families—and good weather. In this difficult economic time, the Buddy Walk committee looked at ways to decrease expenses while still having an enjoyable time for our families.



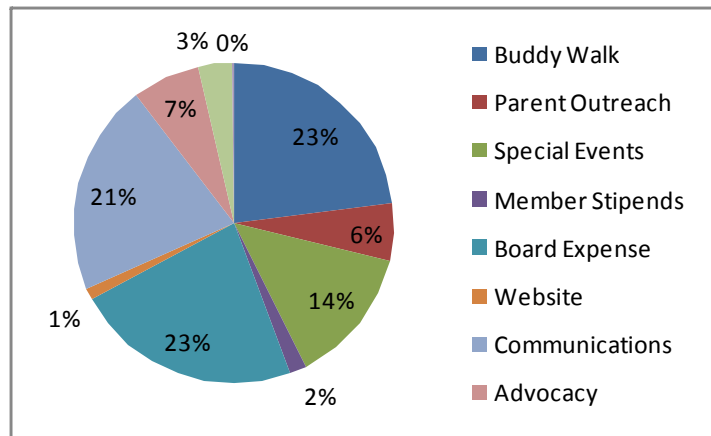
BOARD MEMBERS

Elaine Adams*
Amy Amua-Sekyi
Carena Burtzel*
Jill Connolly*
Shelley Cooper
Lori Eyth *
Matt Gibbons
Steve E. Kudlacek
Allison Machamer
Mary Mc Hale
Katie Schiefen*
Erica Seipold*
Ayman Sharif
Kim Stoneburner*
Lindsey Vogel*
Medical Advisor:
Gary Lerner, M.D.

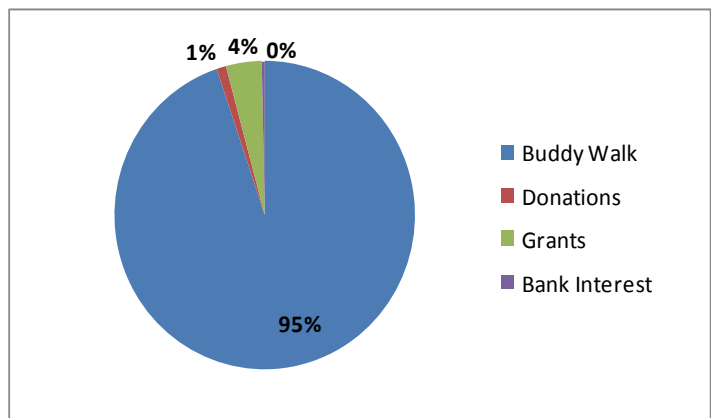
*Completed Board term in 2009



2009 Expenditures	
Buddy Walk	\$ 17,839
Parent Outreach	\$ 4,403
Special Events	\$ 10,690
Member Stipends	\$ 1,280
Board Expense	\$ 17,834
Website	\$ 888
Communications	\$ 16,503
Advocacy	\$ 5,153
DSS Program	\$ 2,731
Bank Charges	\$ 90



2009 Income	
Buddy Walk	\$ 94,439
Donations	\$ 1,024
Grants	\$ 3,800
Bank Interest	\$ 315



**Contact
Us**

ODSPN.ORG



P.O. Box 31686 • Omaha, NE 68131

(402) 991-1800 • info@odspn.org • www.odspn.org