

# **2008 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. Our vision includes:

- Providing access for individuals of all ages and their families to a wide range of opportunities and resources that meet their needs.
- Full participation for individuals of all ages and their families to a wide range of opportunities and resources that inform and support one another.
- An effective coalition with the educational community providing a choice of opportunities for high quality education for individuals with Down syndrome.
- Providing the professional community with services and advice based on available, current and accurate information and acting as advocates for family and individuals with Down syndrome.

# LETTER FROM THE PRESIDENT

As I look back at the many accomplishments that ODSPN has made in 2008, the words that come to my mind are:

**Grateful:** Grateful that ODSPN has a dedicated and outstanding membership who support the events, seminars, and Buddy Walk in so many ways.

**Thankful:** Thankful for excellent board members, who volunteer their time and energy for ODSPN events and who listen to our membership, who let us know what we are doing right and what we need to improve upon.

Amazed: Amazed that with a new location and the challenges that go along with that, the 2008 Buddy Walk raised more money than the 2007 Buddy Walk. And amazed that we had more people attending, more families and others involved in our organization, and new events (along with some familiar ones) during the Buddy Walk.

**Sorry**: Sorry to say Good Bye and Thank You to Mary Beth Bisignano and Jim Burns, who are leaving the ODSPN Board. Mary Beth and Jim were involved in setting up the first ODSPN Board. I thank them for their assistance, guidance, and knowledge during their terms of office.

**Hello**: Hello to our three new ODSPN Board members, Shelley Cooper, Steve E. Kudlacek and Allison Machamer, who began their terms of office in January 2009. They bring experience and enthusiasm to the board. I welcome them and look forward to seeing what great things they have in mind for ODSPN.

**Proud:** Proud on a daily basis of what our group has been able to accomplish. We have partnered with a number of other disability advocacy groups to co-sponsors events, sponsored tables for our membership at fund raising events for other disability organizations, are seen as a resource not only for families but for professionals and other disability groups, AND we continue to meet the needs of our families by providing information, support, and training for all of our families. It really is an extraordinary accomplishment given that our organization is celebrating its 10th year in 2009.

Sincerely,

Mary P. Mc Hale President Omaha Down Syndrome Parents Network

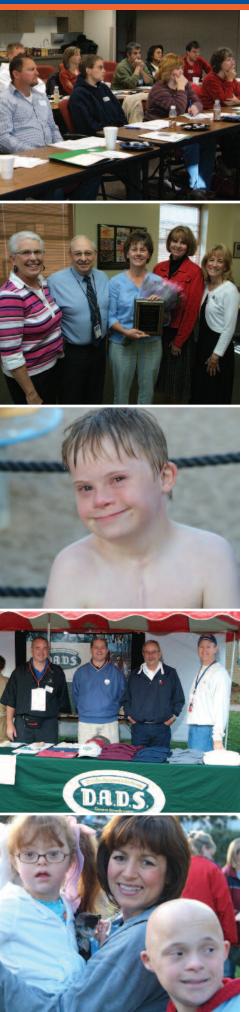
## 2008 ANNUAL REPORT

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## Advocacy

2007 was an extremely active year for ODSPN at the local. state, and national levels. On the national level, ODSPN and its members sent messages to our Congressional Representatives urging them to join the Down Syndrome Congressional Congress. ODSPN met with representatives from Senators Chuck Hagel and Ben Nelson, and Representative Lee Terry's staffs asking for their sponsorship of the Savings Account Bill. ODSPN sent messages to both Houses asking them for their votes for the Kennedy-Brownback Bill, a bill that would require all physicians, when delivering the news that a child would be born with Down syndrome. to present updated information, along with offering the family an opportunity to talk to another family or affiliate group about what it is like to have a child with Down syndrome. President Bush signed this into law in October 2008.

On a state level, families from ODSPN met with state officials to urge them to fully fund the Waiting List. The Waiting list is for parents/guardians of individuals with disabilities to receive services such as Respite, Housing, Services Coordination, etc when the individual becomes 15 years of age or older.Recommendations were then given to the Governor. ODSPN also partnered with The ARC of Omaha to host elected officials at an advocacy event in December 2008.

On a local level, ODSPN began the Down Syndrome Specialist (DSS) program with 17 school districts participating in this program. The DSS program is a partnership with school districts to provide training and information to a DSS for that district so that the DSS is a resource for both the general education teacher, and the special education teacher. This program is modeled after the Kansas City program.

ODSPN awarded the Second Annual Special Educator award to Kay Bataillon, a Special Education teacher in the Birth – 3 program in Ralston Public Schools. ODSPN also presented a \$750 scholarship to a graduate student receiving a Master's in Special Education.

The Advocacy committee also hosted the World Wide Down Syndrome Awareness Day at Barnes & Noble on March 21, along with Parent Peer Presentation Training during National Inclusive Schools Week.

## **Community Outreach**

Changing Lives was revised and revamped so nurses and other health professionals can earn Continuing Education credits. It was presented to nurses at Methodist Hospital. Changing Lives is a curriculum developed by the National Down Syndrome Society for health care professionals on how to present the news that a child will have Down syndrome.

Presentations about personal experiences with having a child with Down syndrome were given to students at UNO, Metro Community College, and Creighton University.

A number of support groups began in 2008: the New Parent Support Group, the Moms group, Sibshops (a partnership with The ARC of Omaha and Autism Action Partnership). A Grandparents and Extended Family Workshop was also co-sponsored by ODSPN.

The D.A.D.S. group also began in 2008. This is a group specifically for dads who have a child with Down syndrome. It is another great example of our membership seeing a need for a group and fulfilling that need.

### Strategic Planning

The ODSPN Board continues to conduct focus groups, surveys, and informal sessions as a part of the Member Advisory Committee (MAC) so we are sure the Board is presenting activities and events for our families. The second Strategic Planning session was held in July 2008 with valuable feedback from the surveys and focus groups.

The ODSPN Board voted to hire its first employee in 2009. This position is intended to be the 'back office person' and take care of the administrative items that happen on a monthly basis.

ODSPN worked with The Rose Theatre to provide drama classes for children with Down syndrome.



#### COMMUNICATIONS

ODSPN continues to communicate with its members in a variety of ways: bi-monthly newsletters, fliers and emails about events and the calendar which is posted on the www.odspn.org website. As a result of survey and focus group feedback, ODSPN is in the process of revising the ODSPN website to make it more user friendly. We'll also add a message board for ODSPN members.

In 2008, printing procedures were streamlined so that fliers and newsletters can be printed at an even greater discount. The ODSPN calendar continues to be a source of information about events and activities for our families.

### BUDDY WALK

The 2008 Buddy Walk was a success in a number of ways: new location, new leadership under Mary Beth Bigisnano, new activities (Radio Disney among others), and a new volunteer process to name just a few. The 2008 Buddy Walk raised over \$115,000 and feedback from our membership is the new location and activities (including the parking) were a hit with all.

Over 100 volunteers gave their time and talents to make this an outstanding success, again. Funds raised at the Buddy Walk are used for programs, special events, seminars, and stipends for ODSPN families throughout the year.





### **EVENTS AND SEMINARS**

Special Events continue to be an important part of ODSPN for its membership. SkateDaze, bowling, swimming and two Parents Night Out activities continue to be widely attended by our membership. New events such as spa afternoon, model car racing, movie afternoon, and co-sponsoring dances for teens and adults with developmental disabilities were a result of feedback from our membership.

Seminars were also an important part of ODSPN in 2008. The Sexuality Seminar in Kansas City in January, Oral Motor Skills Seminar, Sign Language Seminar, Assistive Technology Seminar, and Inclusion Seminar were sessions for parents and professionals.



#### **Board Members**

Elaine Adams Amy Amua-Sekyi Carena Burtzel Jill Connolly Shelley Cooper Lori Eyth Steve E. Kudlacek Allison Machamer Mary McHale Katie Schiefen Erica Seipold Ayman Sharif Kim Stoneburner Lindsey Vogel

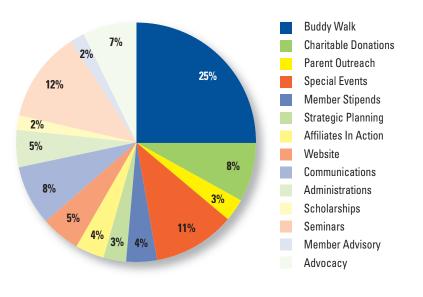
*Medical Advisor:* Gary Lerner, M.D.



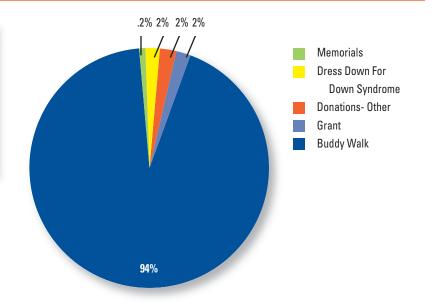


## Financial Overview

2008 EXPENDI	TURES
Buddy Walk	\$24,226
Charitable Donations	\$ 7,500
Parent Outreach	\$ 3,258
Special Events	\$10,393
Member Stipends	\$ 4,065
Strategic Planning	\$ 2,855
Affiliates In Action	\$ 3,983
Website	\$ 4,572
Communications	\$ 8,143
Administrations	\$ 5,287
Scholarships	\$ 2,250
Seminars	\$11,838
Member Advisory	\$ 2,158
Advocacy	\$ 6,947
TOTAL	\$97,475



2008 INCO	ME
Memorials	\$ 250
Dress Down For Down Syndrome	\$ 2,695
Donations- Other	\$ 2,300
Grant	\$ 3,000
Buddy Walk	\$115,760
TOTAL	\$124,005



Contact Us



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