LETTER FROM THE PRESIDENT 2010

As I look back on 2010, I imagine that my feelings are those of a parent whose child is going off on their own in the world, whether it is going on to college, a new job, or out of the house: worry, pride, honor, sadness, and happiness all at the same time. I beg your indulgence as I look back on the last 12 years.

In the very beginning of ODSPN (I think our first name was NDSS Nebraska) in January 1999, 5 families met at Lewis & Clark Middle School on a PRISM night because they had a common interest: meeting other families who had a child with Down syndrome. From there the organization grew to 10 to 20 and now over 400 families and individuals who receive information from ODSPN on a regular basis.

For our 1st Parents Packet, I “borrowed” much of the information from the Down Syndrome Association for Families. From that publication that I would copy at work to the professional packet of information that ODSPN has published for families, expectant families, nurses, doctors—it has been rewarding to see the growth in the organization.

At my last board meeting, I was asked what I have been most proud of with my work with ODSPN. I said the following:

- Presentation at Grand Rounds at UNMC for OB/GYNs and Nurses
- Recognition by the educational and medical communities as a valued subject matter expert
- Hiring of Anne Mancini, Communications Director
- Recognition by families, expectant parents, relatives, etc as the ‘go-to’ place when they had questions about Down syndrome
- Our 1st Buddy Walk in 2002
- Partnerships with other disability groups to present seminars, sessions, etc
- The establishment of the ODSPN board
- Recruiting board members who are not parents of a child with Down syndrome but believe in ODSPN and its mission
- The establishment of an endowment

I could go on with many other items.

I thank Amy Amua-Sekyi and Shelley Cooper for their service on the ODSPN board. The ODSPN board has always boasted excellent members who volunteer their time to make a difference in the lives of individuals with Down syndrome.

I thank those individuals who held fundraisers, who honored ODSPN as memorial recipients, who donated through United Way and who used their companies’ Matching Gifts programs in 2010. These generous donations supported our programs and families.

I thank all past and current ODSPN Board members for having a common vision and their ability to work through some difficult issues while maintaining a professional attitude at board meetings. The meetings were always informative and lively discussions.

I thank the 2010 Buddy Walk committee who raised the bar on donations in another tough economic climate. Our families raised over $95,000 for ODSPN. I am always amazed at what we all accomplish together.

I thank my husband, Joe Holm, for never questioning time spent on ODSPN activities and items. I thank my son, Daniel, for helping me become aware of what is important in life—not only for individuals with Down syndrome, but for all individuals with disabilities.

I will miss many things about being on the ODSPN board (I recommend it to everyone as it is an excellent way to become involved), but like any parent who is seeing their ‘child’ grow up and go off on their own, it is time for new leadership and new beginnings for everyone. I thank you for allowing me to be a part of this journey from its inception to the present and I know that many exciting things are ahead not only for ODSPN, but for my family and me.

Mary P. Mc Hale
BOARD MEMBERS

Amy Amua-Sekyi*
Rob Church
Shelley Cooper*
Matt Gibbons*
Andrew Kloekner
Steve E. Kudlacek
Allison Machamer
Mary Mc Hale*
Jen Shannon
Ayman Sharif
Roberta Tonjes
Medical Advisor: Gary Lerner, M.D.

*Completed Board term in 2010

ADVOCACY

The Down Syndrome Specialist (DSS) program continues to grow. ODSPN hosted breakfasts in January, April and September. Included in the presentations was a speech by self-advocate and a panel discussion on paraprofessionals in the classroom.

ODSPN also held a Transition Seminar for parents who had children transitioning into either kindergarten or middle school.

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

ODPSN invited members to acknowledge their children’s general education classroom teachers for National Inclusive Schools Week in December. ODSPN mailed gift cards to over 30 teachers in the Omaha Metro.

PARENT OUTREACH

ODSPN continued to place baby gifts and new parents guides in hospitals located in the Omaha Metro.

The Down Syndrome Super Moms (DSSM) have been very active, arranging a monthly coffee, field trips to Gigi’s Playhouse, small play dates, and a very successful fundraiser. The DSSM created a beautiful calendar with portraits of ODSPN kids. $2,892.00 was raised.

The G.R.A.N.D.S. held several meetings and a picnic. Members of the group participated in a photo shoot at the Omaha Children’s Museum for future publications.

The D.A.D.S. group continues to meet and arrange outings for families. They are also very involved in the Young Athletes Program.

ODSPN continued the popular program to send Happy Birthday gift cards to our membership.

MEDICAL OUTREACH

ODSPN mailed over 400 packets of prenatal information to OB-GYNs, Pediatricians, and Primary Care Physicians in the first quarter of 2010.

ODSPN presented at a UNMC Nursing Symposium in September and is assisting the College of St Mary Nursing Students by arranging home visits with members.

STRATEGIC PLANNING

The ODSPN Board’s 4th Annual Strategic Planning session was held in August, 2010 and incorporated valuable feedback from the membership surveys and focus groups.

An endowment will be built to support long-range planning for programs and personnel.

EVENTS & SEMINARS

Special Events continue to be an important part of ODSPN for its membership. Over 800 of our members and their families attended events that were held this past year.

Events included Playdaze, A Day at the Movies, Parents Night Out, Pajaramama, Putt-Putt for Teens, Pottery Painting, Omaha Royals Game, Swimming at Pirates Cove, Septemberfest Parade, S’mores (& More!) at Pooley’s Pumpkin Patch, and Bowling at Chops Bowl.

ODSPN partnered with Autism Action Partnership to host Lose the Training Wheels Bike Camp™ in June. Thirty-five bike riders from the community participated in the week-long camp.

Seminars continue to be important for our families. ODSPN partnered with ESU#3 to engage Sean Smith, PhD, to present seminars on Technology for the Classroom.

BUDDY WALK

The 2010 Buddy Walk continued ODSPN’s partnership with UNO. New chairperson Rob Church and his team planned another successful Walk. The 2010 Buddy Walk grew in many ways: sponsors, participation, activities, and fundraising. In addition to our long-term sponsors, 12 new businesses sponsored the Event. A crowd of over 2,300 enjoyed the sun, music, performances and activities and the new route which took Walkers over the bridge into Memorial Park. ODSPN members, sponsors and donors raised $97,000.

GRANTS & PRIVATE DONATIONS

2010 saw an increase in donations through corporate grants and individual donations.

The Iowa West Foundation awarded a $1,500 grant for the expansion of the DSS program to area middle and high schools.

The eBay Foundation awarded a GIVE Team grant of $4,000 for the redesign and reprinting of the New Parents Guide in both English and in Spanish.

Corporate and private donations totaled $12,813.72.
As the mother of a young adult with Down syndrome ODSPN has given both Katie and me the opportunity to become more aware of the advocacy and commitment that the group itself, along with the national organization, has done for those with Down syndrome. Just to be a part of the Buddy Walk and to see the thousands of people that gather each year to “celebrate” these amazing individuals always gives me a renewed sense of strength to continue to advocate for all those with Down syndrome and other disabilities.

As an Early Development Network Services Coordinator I am able to spread the word of ODSPN with my peers as well as with the families I work with directly through the Friday news and the newsletter. There is always good information about upcoming events and activities for all those with disabilities. I also know that when I receive a new referral on a baby with Down syndrome that the parents have received information in the hospital about ODSPN due to the relationship the group has maintained over the years with the hospitals.

Lastly, I am encouraged every day by the younger and older people with Down syndrome that I see in the community working at various jobs and truly being productive members of society. It not only tells me that we continue to break down barriers but that our children, young adults and older adults who happen to have Down syndrome have the potential to be the best they can be and that those without disabilities recognize that. I have always said that if everyone in the world had a “touch” of Down syndrome that it would be a very different world—no holding grudges, treating everybody the same no matter what religion, color or nationality they are, and a heart full of love. We are so very lucky to have them in our lives.

—MaryAnn Schiefen

ODSPN has guided my family in many ways. It has provided information in our native language, it has given us opportunities to participate and enjoy different recreational activities. Thanks to ODSPN, we have met a large number of families with children like our daughter with whom we have shared our experiences. We appreciate the educational events that have allowed us to educate ourselves and to become better parents of a child with a disability. My family and I want to thank all the members and especially Mrs. Mary McHale, who has been an angel in our lives.

—Leticia Franco

We learned moments after her birth that our little Miss Macy had Down Syndrome. This is something my husband and I knew nothing about and had no prior experience with or exposure to. To say we were overwhelmed would be the understatement of the century. We were contacted by a few individuals involved with ODSPN (an organization we did not know existed) within days. Our minds were quickly put at ease once we were made aware of the wide array of LOCAL resources we had at our disposal. It was so refreshing and reassuring to find that there were so many families right here in our community who also share this “common thread.” We were NOT alone.

During this first year we have benefited most by connecting with other families and sharing stories with those who understand and see “eye-to-eye” with us most. I have found the Down Syndrome Super Mom’s group to be an invaluable support system. I enjoy our monthly coffees, and have formed bonds and friendships with the other moms that will truly last a lifetime. We have also taken advantage of some learning materials available through ODSPN’s lending library, which has been helpful.

My husband and I have had a great time meeting and getting to know other families at the various events that ODSPN puts on throughout the year, from swim parties, to football games, to a party a Bounce U. Although Macy is not yet old enough to truly appreciate them, her big sister sure does. I think it’s great the outreach that ODSPN provides the siblings as well.

—Sherri Harnisch
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Net Income $51,464.00