

ANOTHER CDSC SUCCESS: *“Celebrate the Differences”*

The CDSC Convention 2003, “Celebrate the Differences” was held on Saturday, October 11th, at the Marriott-Farmington Hotel and Conference Center. The UConn Center for Excellence in Developmental Disabilities was our co-sponsor. There were approximately 275 parents and professionals in attendance, a record for recent years.

Dr. Richard Villa, the keynote speaker, was entertaining, enlightening, and enthralling. The topics of his keynote and workshop presentations were about making inclusion work, and garnered rave reviews .

Musical entertainment was again provided by Sujet Desai, an accomplished young musician with Down syndrome. Suj was an inspiration to everyone, in addition to adding a touch of class to the event.

There were 16 other break-out workshops, fulfilling the diverse needs of those in attendance.

Susan Saint James, who attended the convention with her son, addressed the audience stressing the importance of our organization in furthering the cause for persons with disabilities.

This year, we tried some new things. We had workshop sessions specifically for teens/young adults with Down syndrome. They included a workshop on

school-to-work transitioning, Karaoke DJ party, and pool party. We had a Silent Auction that raised over \$1,800 to help offset the cost of the convention, which we significantly subsidize. A Convention Program booklet was printed to acknowledge CDSC contributors and serve as a quick reference of service providers.

There were many whose talent and energy went into making this year’s convention the success that it was. They helped with everything; from planning, to presenters, to the member and non-member volunteers that assisted with registration, CDSC tables, and other tasks that day.

We are continuously striving to improve. Comments and surveys from those in attendance pointed up the convention’s strengths and weaknesses. There were several behind-the-scenes areas that were also found to need enhancement.

Thank you to everyone in helping to make the CDSC Convention 2003 the tremendous success that it was. And thank you in advance for making the upcoming 2004 Convention , “Just the Way You Are”, even better!

If you are interested in helping out in any way for the 2004 CDSC convention, please contact me at: kenholewinski@aol.com, or 860-663-2676.

IN THIS ISSUE:

Ready to Read	2
President’s Message	3-4
Statewide Calendar of Events	4
Thank You	5

CONTACT INFORMATION

Call us toll free at
888.486.8537
 in the Hartford area:
860.257.8882
 or visit us at
www.ctdownsyndrome.org

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CDSC Quarterly

Editor: Kathleen Reiss

CDSC Quarterly is published four times per year by the Connecticut Down Syndrome Congress, Inc. We welcome input from parents and professionals. Please help other families by sharing your experiences. Send submissions to: Newsletter Editor c/o Connecticut Down Syndrome Congress, Inc., P.O. Box 340385, Hartford, CT 06134-0385

STATEMENT OF POLICY AND DISCLAIMER

The Connecticut Down Syndrome Congress is a non profit organization which acts as a resource for families and professionals involved with a person who has Down Syndrome. Its vision is to improve the lives of persons with Down Syndrome, and to encourage the community at large to receive and embrace them. This newsletter reports items of interest relating to Down Syndrome and will provide a forum for others. The Congress does not promote or recommend any therapy, treatment, etc. We will not espouse any particular political or religious view. Individuals or organizations referred to do not necessarily endorse this publication or its editor. The editor reserves the right to make corrections as appropriate, and in accord with established editorial practice in material submitted for publication.

CONTRIBUTIONS

The Connecticut Down Syndrome Congress, Inc. is a not-for-profit organization registered with the Internal Revenue Service to accept tax-deductible contributions. Contributions are deductible to the extent permitted by law. All funds received are appreciated and will be used to further the objective of the the Connecticut Down Syndrome Congress, Inc.

HOW CAN I HELP MY CHILD Be Ready to Read and Ready to Learn?

1. Talk to your infant and toddler to help him learn to speak and understand the meaning of words. Point to objects that are near and describe them as you play and do daily activities together. Having a large vocabulary gives a child a great start when he enters school.
2. Read to your baby every day starting at six months of age. Reading and playing with books is a wonderful way to spend special time with her. Hearing words over and over helps her become familiar with them. Reading to your baby is one of the best ways to help her learn.
3. Use sounds, songs, gestures and words that rhyme to help your baby learn about language and its many uses. Babies need to hear language from a human being. Television is just noise to a baby.
4. Point out the printed words in your home and other places you take your child such as the grocery store. Spend as much time listening to your child as you do talking to him.
5. Take children's books and writing materials with you whenever you leave home. This gives your child fun activities to entertain and occupy him while traveling and going to the doctor's office or other appointments.
6. Create a quiet, special place in your home for your child to read, write and draw. Keep books and other reading materials where your child can easily reach them.
7. Help your child see that reading is important. Set a good example for your child by reading books, newspapers and magazines.
8. Limit the amount and type of television you and your child watch. Better yet, turn off the television and spend more time cuddling and reading books with your child. The time and attention you give your child has many benefits beyond helping him be ready for success in school.
9. Reach out to libraries and community and faith-based organizations. These organizations can:
 - Help you find age-appropriate books to use at home with your child;
 - Show you creative ways to use books with your child and other tips to help her learn; and
 - Provide year-round children's reading and educational activities.

For more information visit

<http://www.ed.gov/parents/academic/help/partnership.html>
or call 1-800-USA-LEARN

President's Message

NOVEMBER 2003

When I attended my first CDSC board meeting five years ago, I sat at the table, too intimidated to speak. There were about 8 board members there, including Dr. Bob Greenstein, the CDSC's medical advisor. After the meeting, I started to tell Dr. Greenstein about our daughter's birth. Every family has their story about the birth of their child with DS, and many of those stories were like ours. The hospital staff was trained to deal medically with the child, but not with the emotions of our family. I burst into tears when telling Dr. Greenstein the story of the geneticist who met with us shortly after her birth, and began the conversation with "Your daughter has Down syndrome, she will never". Dr. Greenstein listened patiently, nodding every once in awhile in sympathy. Then he said, "OK, enough crying. You have work to do. Get on with it, and raise this child."

Nobody before, or since, has given me such good advice about raising a child with Down syndrome. I kept coming to the board meetings, and eventually worked up enough courage to actually offer an opinion or contribute to the discussion. Some of the current board members might wish for the days when I had a lot less to say!

Through our family's association with the CDSC, I drew strength from the other families I met. I learned how to advocate for our daughter from the conferences sponsored by the CDSC. I learned about legislation at the local and state level that would have a profound effect on my child, and how I could contact lawmakers before they voted. I have also met people that I never would have had Krista been born without DS. Some of these people have become family.

Krista is now 6 years old and fully included in the first grade of our local elementary school. I sometimes think back to the geneticist that told us all the things our daughter would not do. So far, she has been wrong on all her dire predictions. Raising our daughter is much like raising our "typical" son, full of joy and challenges and some sleepless nights. Our family is, however, full of optimism for her future.

It is therefore, a privilege to serve as President of an organization that has given so much support to our family.

Our November board meeting will be devoted to strategic planning. Because we are an all-volunteer board with limited financial resources, we must prioritize which projects the CDSC can financially and logistically devote its efforts to in the coming year. Some of the projects under review are; sponsoring a conference on current research from the UK, partnering with hospitals to provide a more balanced and caring approach to newborns with DS, partnering with the ARC to provide our members with information on state and local legislation, expanding our fundraising efforts, updating our video about life with Down syndrome, as well as other worthy projects. Let the board know which projects are important to you. *Please feel free to contact me at (860) 663-2676, or at LynnCholewinski@aol.com. The CDSC board meetings are open to everyone. Please consider attending one.*

-Lynn Cholewinski

CDSC Calendars for Sale

Beautiful photos of our children with inspirational messages for each month make this 2004 calendar the perfect holiday gift for teachers, family and friends.

\$12.00 per calendar,
or **\$10.00** per calendar for orders
of ten or more.

**Send 2004 Calendar order form to
CDSC P.O. Box 340385,
Hartford, CT 06134-0385
OR Fax 860-257-1650**

Quantity _____ X Price _____ = \$ _____

(Postage 0-10 calendars = \$1.25; 10 or more = \$2.50)

Total amount enclosed \$ _____

Please use the order form below.

Check Enclosed made payable to CDSC **OR** Charge my credit card

Visa MC Card number _____

Name on card _____

Billing Street Address _____ City _____ State _____ ZIP _____

Expiration date _____ Amount \$ _____

Please bill my credit card for amount indicated above.

Signature _____ Date _____

Mail calendars to:

Name _____

Street Address _____ City _____ State _____ ZIP _____

Statewide Calendar of Events

for program details please visit www.spednet.org

CDSC NOVEMBER / DECEMBER CALENDAR

Please contact the CDSC at 888-486-8537 or admin@ctdownsyndrome.org to have your e-mail address added to our e-mailing list. To learn more about the CDSC visit us at www.ctdownsyndrome.org

The vision of the Connecticut Down Syndrome Congress is to improve the lives of persons with Down Syndrome, and to encourage the community-at-large to receive and embrace them.

- Nov 21 THE MENTAL HEALTH ASSOCIATION OF CT PRESENTS: THE TRAUMA DEBATE: TREATMENT ADVANCES AND CONTROVERSIES. Ramada Plaza Hotel, Meriden, CT *For more information call 1-800-842-*1501, ext. 13 or 10.*
- Nov 21 & 22, CT FAMILY SUPPORT CONFERENCE "MAKING CONNECTIONS TO BUILD SUPPORTS" Farmington, CT *For more information, please contact Molly Cole at (860) 563-3232 or FAVORCT@AOL.com*
- Nov 21 & 22, "INDIVIDUALS AND FAMILIES LEADING SELF-DETERMINED LIVES" A COMBINED FAMILY SUPPORT AND SELF-DETERMINATION CONFERENCE. Farmington, CT. *For more information, please contact Molly Cole at (860) 563-3232 or FAVORCT@aol.com or Yvette Johnson at (860) 418-8709 or yvette.johnson@po.state.ct.us*
- Nov 22 CDSC PLAYGROUP IN WINDSOR. *For more information please call Patti Silva at 860-529-7766 and cakes01@cox.net or Chris McAuliffe at 860-683-2535 and mack1200@aol.com.*
- Nov 23 SMART KIDS WITH LEARNING DISABILITIES presents Tade Reen. *For more info, visit www.SmartKidswithLD.org*
- Nov 24 DISCUSSION ON SPECIAL EDUCATION in Darien. *For questions, call the YWCA (203) 655-2535.*
- Nov 25 THE ABC'S OF DEVELOPING AN EFFECTIVE IEP New Canaan. *Please RSVP to Anne Eason at (203) 966-9709 or Beth Lurie (203) 966-2982.*
- Dec 2 PIZZA MOMS IN THE FAIRFIELD COUNTY AREA in Darien *If you are interested in coming please email Nanette at: Nanette618@yahoo.com*
- Dec 6 A MORNING OF INFORMATION & INSPIRATION WITH RICK LAVOIE, Norwalk. *Please RSVP to Lory McCabe at (203) 761-9171.*
- Dec 6 CDSC PLAYGROUP IN COLCHESTER at the Cragin Memorial Library from 11 to noon. *For more info please call Karen Zbierski at 860-873-8615*
- Dec 13 CDSC PLAYGROUP IN LITCHFIELD COUNTY. *For more information call Penny at 860-210-0048 or ct1Penny@aol.com*
- Dec 13 CDSC PLAYGROUP IN WINDSOR. *For more information please call Patti Silva at 860-529-7766 and cakes01@cox.net or Chris McAuliffe at 860-683-2535 and mack1200@aol.com.*
- Dec 16 CDSC MOM'S NIGHT OUT in at the Olive Garden in Manchester. *For more information, to RSVP or for directions please call Debbie Keller at 860-228-4226*

This newsletter reports items of interest relating to Down syndrome and will provide a forum for others.

The Congress does not promote or recommend any therapy, treatment, etc.

THANK YOU! THANK YOU! THANK YOU!

To everyone who came out to Lenny & Joe's for the fundraiser—We raised \$850 and had a great time! I have been asked repeatedly the question:

"What are you raising funds for?"

Did you know?

- We fund 100% of the annual picnic
- We give scholarships
- We give mini-grants
- We sponsor educational seminars
- We sponsor playgroups
- We absorb over 50% of the cost per registrant for the CDSC convention
- We absorb 100% of the cost for any one that is unable to pay for their membership or the CDSC convention
- We purchase and distribute literature to schools, libraries, and professionals
- We purchase new parents kits

We have a vision to improve the lives of persons with Down syndrome, and to encourage the community-at-large to receive and embrace them. We can do so much and make such a difference, with the appropriate financial support.

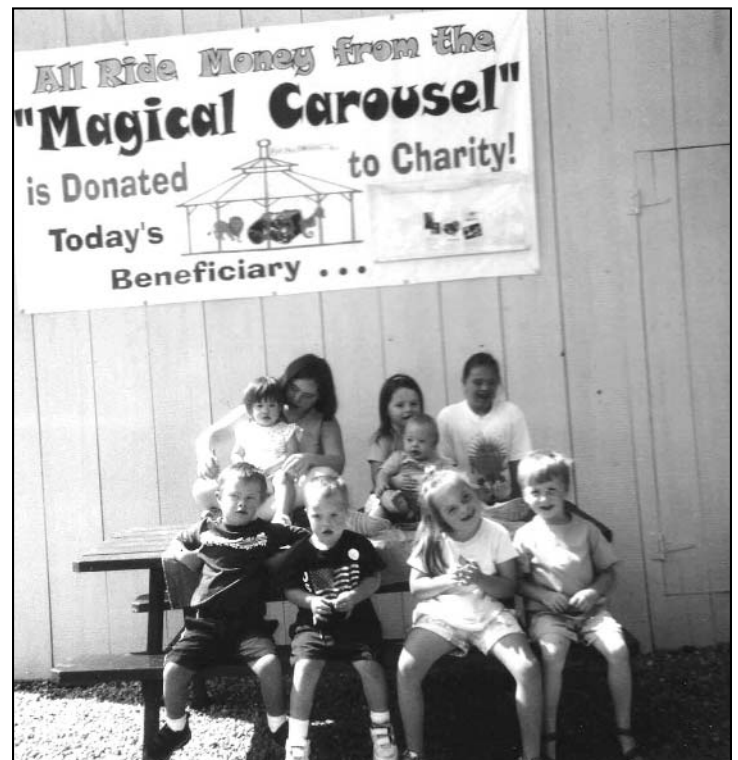
As January approaches and I begin the efforts of launching another year of fundraising, I hope everyone will be receptive and I welcome any ideas, concerns, input, and involvement with these efforts.

Personally, I think CDSC is a GREAT cause, (OK I am a little bias.)

—Jaye Carlson



Above, the Carousel ride at Lenny & Joe's in Madison was great success. At right these young supporters take a break from the fun to pose for a photo.





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CDSC Membership Application/Renewal

Name _____ Occupation _____
 Street/P.O. Box _____
 City _____ County _____
 State _____ Zip _____ Phone _____ Email _____

MEMBERSHIP TYPE

Family New (\$25)
 Family Renewal (\$35)
 Professional (\$35)
 My Additional Contribution

FAMILY INFORMATION:

Child's Name	Date of Birth	Has D.S.?
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____
5. _____	_____	_____

Do you wish to serve on a committee? Yes No (If "Yes", we may be contacting you.)

Please enclose check payable to the Connecticut Down Syndrome Congress, Inc., PO. Box 340385, Hartford, CT 06134-0385. Membership may be either an individual, family or professional basis. A family membership entitles both parents to hold office and vote. We welcome membership from any and all interested individuals, families, businesses and organizations. Your contribution to CDSC, Inc., is tax deductible.

The above information will be kept confidential unless the following box is checked.

REMEMBER: A subscription to the CDSC Quarterly makes a great gift for teachers and therapists!