



Quarterly

CONNECTICUT
down syndrome
CONGRESS

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WINTER 2002

As I sit here watching my senior year in high school fly by, I come to the realization that a chapter of my life is ending and I am about to embark on a new adventure. Looking back over the past seventeen years of my life I see all that I have been through and all that I have accomplished, all of which I share with my sister, Lauren. Lauren has been an inspirational influence and loyal friend to me since she was born in February of 1987. Lauren is not like most younger siblings, she is special. Three weeks after Lauren was born our family was told that Lauren had Down syndrome. Down syndrome is a genetic disorder, which usually causes delays in physical and intellectual development. At four years old I didn't really understand this nor did I care. A lot of things have changed in the fourteen years since Lauren was born but one thing will never change, Lauren will always be my little sister and best friend with whom I share an incredibly close and special bond.

When I was little having a sister with special needs was extremely difficult. Lauren required a lot of my parents' attention and time. My parents spent weeks in court fighting the state so Lauren could be mainstreamed into regular education classes. As a kindergartner I knew little about the impact that my parents were making for all children with disabilities in the state of Connecticut. I did, however, understand that I spent weeks at a neighbor's house and saw very little of my parents. As a young child it sometimes seemed like everything was about Lauren, although I knew this was not true because of the effort my parents always made to support me. Lauren simply demanded more of their time because of her special needs. Through the years this helped teach me to become more independent and mature.

When I got to middle school things started to change. I was old enough to stay home alone and watch Lauren. We began spending a lot of time together watching television, playing games, or running around the neighborhood. In middle school I also became involved in more activities such as sports, clubs, and after school programs. Lauren looked up to me in all that I did either by following in my footsteps or cheering me on. I knew that my little sister was watching every step I took and that I had to set a good example to make the right choices in life. Because of Lauren I became involved with Special Olympics, which has since become a big part of my life. Since seventh grade I have volunteered as a coach, chaperone and unified partner on the Wethersfield Special Olympics team. Through these experiences I believe I have become a more compassionate and caring person and I can thank Lauren for getting me involved with such an inspirational program.

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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

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Continued from Cover...

Over the past few years I have developed a very special bond with my sister. Since I began driving I frequently shuttle her to some of her activities, and the time we spend together in the car is priceless. Over the summer Lauren came to visit me at work when there were thunderstorms and she was too scared to stay home alone. We took vacations and spent endless hours together in a car traveling from one place to another, singing songs, watching movies and falling asleep hand in hand with the comfort that we were together. Once again we are attending the same school for the first time since I was in sixth grade. Every morning I drive my sister to school, I spend a few periods a day in her classroom helping out, and then I drive her home again. Some days I stay home with her after school and we hang out, other days I have a practice, and other days she comes back to school to watch me play in a game. On weekends we frequently hang out with my friends, taking trips to football games or the movies. She looks up to my friends and is close to many of them. I take comfort in knowing that in my absence next year they will look out for her.

Our relationship is different than most sisters and hard to describe. It is impossible for me to stay mad at her when she acts like a typical little sister and bothers me but pride comes easily when a medal is placed upon her neck during Special Olympics. A hug from her can stop my tears from flowing, her small hand can guide me in the right direction and a big grin on her face can make my day. Lauren has made an impact on the lives of all that have known her but the impact she has made on my life is indescribable.

*—By Elizabeth Gray
Senior at Wethersfield High School
Daughter of Larry and Joan Gray*

President's Message

FEBRUARY 2002

Many of you have read in the news about trouble at the state Department of Mental Retardation. Late last year, the Hartford Courant published a series about questionable deaths at group homes funded and licensed by DMR. According to the Courant, one in every 10 deaths in a Connecticut group home involves questionable circumstances such as neglect or staff error. Starting salary for nonunionized staff at group homes is only about \$11/hour, making it difficult to attract and retain enough caring and capable people to work with our children. The state's Program Review and Investigation Committee will likely decide in late January or early February to go forward with an investigation.

Why does this matter to us?

DMR is a state agency whose mandate is to assist persons with mental retardation, defined by Connecticut statute as a person with IQ less than 70 and demonstrated deficits in adaptive behavior, both in evidence before the age of 18. DMR runs the state's Birth to Three program, through which children with Down syndrome receive early intervention teachings and therapies. In addition, DMR offers information and referral, respite care, leisure and recreation opportunities, employment and day services, residential options, advocacy and parent support, self-advocacy, assistive technology, and long term and estate planning. DMR provides direct services, such as Birth to Three services or job coaches, and also contracts out to private non-profit and for-profit organizations to deliver services.

DMR is an agency in trouble. In addition to the recent news about deaths at group homes, a class action lawsuit was filed last October by ARC/CT and ten people currently on the waiting list for residential support. In the complaint, plaintiffs (the good guys) "seek to remedy the pervasive, systematic, and continuing failure [of DMR] to provide them with necessary services in a reasonably prompt manner as required by the Medicaid Act, to be provided in the most integrated setting appropriate...as consistent with the American with Disabilities Act." Residential support includes all housing arrangements: independent living, supported living arrangements, and group home placement. Similar lawsuits have been filed in nineteen other states; all of them have been settled or ruled in favor of the plaintiffs. Thus it is probable that after a few years of foot-dragging, the state will be forced to allocate the funding to develop new residential supports for over 1400 persons.

What can we do? It is important that our legislators know that we are voters who care about what happens to DMR. As individuals and as an organization, we can email our state senators and representatives, demanding that persons with developmental disabilities receive the services to which they are entitled, delivered in a safe environment, and that the state agency that oversees these services is run in an efficient and effective manner. We can also speak out at legislative hearings and regional meetings, and write opinion pieces for our local newspapers. If you are interested in helping out in this effort, please contact me, so that our numbers are put to most effective use.

To find out who your state senator and representative is, go to the General Assembly's website, www.cga.state.ct.us, and click on "Find Senator by Map" or "Find Representative by Map."

—Beth Lurie

STATEWIDE CALENDAR OF EVENTS

- MARCH 2: FAIRFIELD COUNTY 2ND ANNUAL GROWN-UPS GET TOGETHER.
Cocktails, Hors D'Oeuvres and Conversation.
Bring your favorite hors d'oeuvre or dessert.
Hosted by Barbara and Rob Rosiello. RSVP 203-454-7995
- MARCH 11: CDSC BOARD OF DIRECTORS MONTHLY MEETING.
- MARCH 13: STEPS OF DARIEN PRESENTS ANDREW A. FEINSTEIN, ESQ., "Recent Developments in Special Education Law."
11:45am-1:30pm.
Darien Library, 35 Leroy Ave., Darien, CT.
For more info, call STEPS at 203-655-2535, ext. 61.
- MARCH 16: LITCHFIELD COUNTY- SKY TOP LANES BOWLING.
10:30AM -Fun for the entire family.
For more info call 860-210-0048.
- MARCH 25: FAIRFIELD COUNTY MOMS NIGHT OUT.
Bertucci's, Post Road, Westport at 7:30 PM.
For more info call Barbara Rosiello 203-454-7995.
- APRIL 5-7: NATIONAL PARENT TO PARENT CONFERENCE, Philadelphia, PA.
For more info, visit www.parenttoparent.org.
- APRIL 10: STEPS OF DARIEN PRESENTS EILEEN LUDDY, DIRECTOR, LUDDY AND ASSOCIATES, "DESIGNING INSTRUCTION AND ADAPTING CURRICULUM."
Learn how effective teams design instruction for students with special needs in the regular classrooms.
11:45am-1:30pm.
Darien Library, 35 Leroy Ave., Darien, CT.
For more info, call STEPS at 203-655-2535, ext. 61.
- APRIL 11: CDSC BOARD OF DIRECTORS MONTHLY MEETING.
- APRIL 23: FAIRFIELD COUNTY MOMS NIGHT OUT.
Bertucci's, Post Road, Westport at 7:30 PM.
For more info call Barbara Rosiello 203-454-7995.
- APRIL 24: LITCHFIELD COUNTY PARENT'S NIGHT OUT.
Aspen Garden Restaurant at 7:00 PM.
For more info call 860-210-0048.
- APRIL 27: AIM HIGH/DOWN SYNDROME'S ANNUAL CONFERENCE, "BEYOND OUR WILDEST DREAMS."
St. Anne's Institute, Albany, NY.
Keynote speaker is Chris Burke.
For more info, check out www.aim-high.org.
- MAY 8: CDSC BOARD OF DIRECTORS MONTHLY MEETING.
- MAY 19: CDSC 12TH ANNUAL GOLF TOURNAMENT
Twin Hills Country Club.
For more info call Kathi or Bob Reiss 203-937-7931.
- May 23: FAIRFIELD COUNTY MOMS NIGHT OUT.
Bertucci's, Post Road, Westport at 7:30 PM.
For more info call Barbara Rosiello 203-454-7995.

VERY SUCCESSFUL CONFERENCE WITH DR. LIBBY KUMIN

What a great weekend we had with Dr. Libby Kumin and 200 participants! Dr. Kumin was in Darien on November 10th and 11th presenting School Talk: Language Skills for Inclusion from Preschool to Middle School for Children with Down Syndrome. Dr. Kumin is a nationally renowned author and lecturer on communication and related issues regarding children and adults with Down syndrome. She is a professor and graduate program director in the Department of Speech-Language Pathology/Audiology at Loyola College in Maryland. She has recently published her second book Classroom Language Skills in Children with Down Syndrome: A Guide for Parents and Teachers. This book is available through Woodbine House Publishers.

About 100 professionals attended the workshop on Saturday and everyone gave very positive feedback on the speaker, content and material, lunch, site and organization, Then about 100 parents attended on Sunday - and we got the same feedback from them. We had participants from Connecticut, Rhode Island, Massachusetts, New York and even one couple came all the way from Minnesota.

This conference was organized in conjunction with a parent group from Darien STEP's of Darien. It was also co-sponsored by STAR, ARC of Greenwich/Stamford and DMR. So it was the efforts of many that made this such a successful event.

For those of you who attended, thanks for coming and we hope it was a meaningful day for you. For those who missed it, hope you'll be able to attend future educational programs.

—Submitted by Catherine Klein

NOTE: Libby Kumin is currently working on a new project and is asking parents of children with Down Syndrome between the ages of 1-21 years to complete a Speech Intelligibility Survey. The few minutes it will take to complete this survey will be a tremendous help in our efforts to better understand and treat speech related problems for children with Down Syndrome.

The survey can be completed on-line at <http://www.loyola.edu/speechpath/survey> or can call CDSC at 888-486-8537 to have a survey mailed to you.

Speech and Language Pathologist

Lori L. Overland, M.S., CCC-SLP

I am conducting a doctoral research project which will explore the relationship between the oral motor skills used for feeding and the oral motor skills used for speech production. This study will focus on a young Down syndrome population. Participants must be between nine and twelve months of age at the onset of the study, and meet the following requirements:

- A diagnosis of Down Syndrome secondary to Trisomy 21.
- No complicating health issues which could require intervention or hospitalization during the course of the study (i.e., cardiac concerns, respiratory issues, cleft lip/palate, leukemia, hearing impairment).
- No previous oral motor therapy.
- Caretakers must be willing to implement a home feeding program and keep interim data for a three-month period.

Study participants will be evaluated at the onset of the project, two weeks into the program, at the midway point and at the completion of the program.

If you are interested in having your child participate in this project, please contact Lori Overland immediately.

(914) 533-5010

(203) 834-2633

E-Mail – OROMOTORLO@AOL.COM

Maybe Chris Burke started this way

Want the world to see how gorgeous your child is, every day, for a whole month? Submit a photo of your child/ children for consideration in the 1st ever CDSC calendar. These calendars will be sold as a fundraiser for CDSC beginning in October 2002. Please include the child's name, age, address, and phone number, and send it to Pam Wilson, 18 Davis Drive, Guilford, CT 06437. *Questions can be directed to Pam at 203-453-4427.*

Litchfield County News

Playgroups, for ages five and under, are held the second Saturday of each month. Parent's night out scheduled April 24 at Aspen Garden Restaurant, in Litchfield, at 7:00 PM. Join us for Bowling on March 16 at 10:30 AM, at Sky Top Lanes in Torrington. *For more information please call 860-210-0048.*

2002 Golf Tournament

The 12th Annual CDSC Golf Tournament will be held on May 19th at Twin Hills Country Club in Coventry. Details will be forwarded separately as the tournament date gets closer. But the success of our tournament relies heavily on contributions from our community. If you are aware of a corporation or small business willing to make a contribution to support the CDSC please let us know and we can send out a more formal letter and/or sponsor form. Contributions can be a raffle prize, a food donation for the tournament participants or Tee sponsorship.

For more info call Bob or Kathi @ 203-937-7931.

Hartford County News

Playgroup for newborns to PreK children and their parents/guardians, siblings and friends. All are welcome to come and share the fun. The playgroup is free and will be held monthly at the Windsor Public Library. Toys and lots of space for the kids to play and grown-ups to talk is provided. No registration required, just drop in at the Windsor Library and meet some new friends.

For more info call Chris @ 860-683-2535.



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CDSC Membership Application/Renewal

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

MEMBERSHIP TYPE	
<input type="checkbox"/> New	<input type="checkbox"/> Renewal
<input type="checkbox"/> Individual	<input type="checkbox"/> Family
<input type="checkbox"/> Professional	
<input type="checkbox"/> Other (please specify) _____	

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 dues of \$25.00. My additional contribution of \$_____ is enclosed. Please make check payable to the Connecticut Down Syndrome Congress, Inc., P.O. 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.