

Down Syndrome is Contagious—A Mother's Essay

By Wendy Golden

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Down syndrome is a genetic disorder characterized by a triplication of the genetic material on the 21st chromosome. This trisomy occurs with the first division of the developing zygote. As a result, there is extra genetic material present in every cell of the individual. Recently, science has discovered that this cellular abnormality is highly contagious. As a result, family members (and even friends) of individuals with Down syndrome often find themselves exhibiting dramatic changes due to this "something extra" permeating their bodies at a cellular level. These changes manifest themselves in a number of ways.

"Something extra" in the visual cortex results in parents who view the world differently. In addition to seeing things in an entirely new light, these parents also report having an increased ability to focus on what is important. Spontaneous appearance of tears of joy have also been confirmed.

The section of the brain used in logical thought undergoes dramatic changes. Parents suddenly find themselves able to comprehend and discuss complex medical procedures. Ability to decipher long strings of acronyms appears almost immediately and it is not uncommon for affected parents of newborns to be able to differentiate between AVD, VSD, and PDA. Familiarity with G-tubes, Pic lines and the NICU is another side effect.

Over time, the entire nervous system is transformed, enabling parents to perform tasks previously thought impossible. This change results in individuals finding the nerve to advocate before large crowds, speak to classrooms of medical students, and educate the population at large about issues they are passionate about. These changes are closely tied in to dysfunctions in verbal abilities which make it virtually impossible for parents to bite their tongue. Often individuals who previously considered themselves reserved will find themselves outspoken and effective communicators.

The pulmonary system is altered to a dramatic extent. Parents report having their breath taken away at the slightest prompting.

The cardiovascular system develops similar vulnerabilities and reports of hearts pounding loudly and swelling unexpectedly are not uncommon. One mother reported that her heart skipped a beat when her son smiled at her for the first time.

The extremities are also altered. Arms reach out to strangers for support and in turn hands comfort and nurture those in need. Legs strengthen and balance improves, allowing parents to stand firm in their convictions and walk without faltering even when shouldering a heavy load.

Scientists are baffled by the widespread scope of these symptoms. Equally perplexing is the response of those afflicted. Parents readily acknowledge fundamental changes in their being, however, almost universally declare a preference for their new, altered level of functioning. "I wouldn't change a thing" is a common refrain. Apparently, the presence of a "little something extra" enhances the lives of individuals fortunate enough to be infected.

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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.

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Medical Advice Column

CERVICAL NECK INSTABILITY: REMINDER

The first and second cervical vertebrae (neck bones) are important in providing strength and stability to keeping the head upright. The second cervical vertebra has an upward extension (the odontoid process) which fits into the first cervical vertebra for extra support. A loose-fitting odontoid process leads to instability ("wobbles") and in a very small number (< 1%) to dislocation and possible spinal cord injury. Signs of injury include complaints of pain, head tilting, loss of bladder/bowel control and tripping/falling as a new problem.

The measurement of the odontoid interval is performed by a lateral view xray of the cervical neck in flexion (head flexed forward) and extension (head stretched back), and should be less than 5.0 millimeters. If normal, no further measurements are required. If greater than 5.0 mm, the diagnosis of "odontoid instability" is established and the child should be referred to a neurosurgeon for evaluation. In addition, the child should not participate in tumbling (neck flexion) or diving. Other types of exercise, such as running, swimming, and hiking are permitted.

The CDSC recommends that the odontoid interval should be obtained between the ages of 4-6 years. It is unnecessary to perform the study before this time.

—Dr. Robert Greenstein

President's Message

NOVEMBER 2002

It was great to see old friends and new at our 17th annual convention, "Life As We Know It," last month. You can read more about the convention later in this newsletter. Special thanks go to Ken Cholewinski, convention organizer, along with volunteers Lynn Cholewinski, Barbara Rosiello, and Kathy Lopes; our co-sponsor, the University of Connecticut A.J. Papanikou Center for Excellence in Developmental Disabilities; Tom Smith, Walter Klein, and Paul McAlenney of the Scholarship Committee; and Penny Inferrera, Lori Murphy, and Jay Lurie of the Awards Committee, for putting together such a lively and informative program. A few years ago, a membership survey ranked the convention as the single most important thing that CDSC does, and this year it was done especially well. It is likely that next year we will go back to the Farmington Marriott, so jot it down in your calendars! If there are any topics that you would like to hear about in a workshop, drop us a line.

Last week I had two people, on very different occasions, remark to me that Eve is so "high functioning, for her diagnosis." One person was a green-behind-the-ears (i.e., younger than me!) pediatrician at the group practice we frequent. The other was a teacher who knows Eve from around school. Both should have known better. On the one hand, I too am very happy that Eve is able to do so many things that are often taken for granted – like walk, and talk, and read, and other important life skills. And it's always nice to hear someone give your kid a compliment, especially your kid with so-called "special needs." On the other hand, the phrase "high functioning (for someone with Down syndrome)" implies that it's a surprise that Eve can do all these things. It shows the bias that exists in many well-intentioned people. So I'm trying to decide the best response to people who say such things, without biting their heads off. Here's what I've got so far:

There's the neighborly reply: "Yes, Eve is doing well, but more importantly, people with Down syndrome can do so much more than they have been given credit for. This generation of young people with Down syndrome, who are the first to get a decent shot at an education, will truly break down barriers. The low expectations of the past will be forgotten as we see more people with Down syndrome participating, in every way, in adult community life."

Or there's the more militant: "Yes, Eve is doing well, even for someone with no diagnosis. We expect no less from her, because people will always live up or down to whatever expectations are set for them. If Eve is to succeed in the real world, we have to derive our expectations from the real world, and not from some outdated standard of how a person with Down syndrome functions."

If I'm in a bad mood already, I fear that I might snap back: "Yes, Eve is doing well, but why do you have to qualify the compliment with, 'for her diagnosis'? I can only hope that it's due to ignorance, and not fear, that you hold such low expectations for people with her diagnosis. If you, and society at large, looked beyond the 'Down syndrome' label to see her as an individual with the potential to learn, and to make a contribution to our society as an adult, then people with disabilities and their families wouldn't have to fight for an inclusive education, for real jobs in the community, and I wouldn't be shouting at you right now!"

–Beth Lurie

STATEWIDE CALENDAR OF EVENTS

- DECEMBER 9: MONDAY, 7:00 PM. AN INTRODUCTION TO THE PICTURE EXCHANGE COMMUNICATION SYSTEM WITH JAN CALABRO, M.A., C.A.S. Sponsored by Connecticut Center for Child Development, 925 Bridgeport Avenue, Milford, CT 06460. Seating is limited and early reservations are recommended. *Call Holly Sickles to make reservations at (203) 882-8810, extension 10.* Due to space limitations, please notify us of cancellations as early as possible so that others can be accommodated. In case of inclement weather, call extension 23 to confirm that CCCD will be open.
- DECEMBER 11: LIFE PLANNING: A PRIMER FOR SPECIAL FAMILIES WITH MICHAEL BELOFF, FINANCIAL ADVISOR UBS PAINE WEBBER. Wednesday. 7:00 pm. Stamford Government Center, 888 Washington Blvd., 5th floor board room. *Please bring picture ID for security checkpoint. Sponsored by SCOPES. www.scopesnetwork.org.*
- December 11 - 14: TASH CONFERENCE, Boston, MA. *Check www.tash.org for more info.* TASH members believe that all people, regardless of their label or perceived level of disability, should have the supports they need to direct the course of their own lives, and to live and participate successfully in the community. All means All! The 2002 TASH Conference is a showcase of innovative "how-to" strategies, research, and empowering stories. Each of the over 350 breakout sessions include cutting-edge, practical information about changing images, attitudes and systems to empower individuals with disabilities and their families.
- JANUARY 6, MONDAY. HOW TO PROMOTE PRE-WRITING & HANDWRITING IN THE YOUNG CHILD. This discussion will focus on the components necessary for a child to be successful when coloring, drawing and writing. A brief introduction to "Handwriting Without Tears" a multi-sensory program. Sponsored by STEPS of Darien. Held at the Darien Library, 9:30 to 11:30, 35 Leroy Avenue, Darien. *To RSVP or to find out more about STEP's, please call the YWCA at (203) 655-2535 extension 61. You can also reach them at YWCASTEPSDarien@aol.com.*
- JANUARY 7, TUESDAY, 7:00 PM. TOILET TRAINING. Speaker Cresse Snyder. Sponsored by Connecticut Center for Child Development, 925 Bridgeport Avenue, Milford, CT 06460. Seating is limited and early reservations are recommended. *Call Holly Sickles to make reservations at (203) 882-8810, extension 10.*
- JANUARY 8, PLANNING FOR SUMMER 2003: SUCCESS STORIES. Wednesday. 7:00 pm networking/refreshments, 7:30 pm program. Stamford Government Center, 888 Washington Blvd., 5th floor board room. *Please bring picture ID for security checkpoint. . Sponsored by SCOPES. www.scopesnetwork.org.*
- JANUARY 16, CURRICULUM MODIFICATIONS. Michele Schneider, MS, in Special Education, is the Founder and Director of the Pound Ridge Learning Center in Pound Ridge, NY and is a Special Education Advocate and Learning Consultant. How to modify and adapt curriculum and homework so all students can succeed. Held at Waveny House, Waveny Park, South Avenue, New Canaan, CT. Thursday, 10 to noon. Sponsored by SPED*NET New Canaan. *Please RSVP Anne at (203) 966-9709 or Beth at (203) 966-2982.*
- FEBRUARY 3: MONDAY. PERSON CENTERED PLANNING. This lecture will cover some of the various planning tools used to assist all team members with a child who has an IEP (Individualized Education Plan). Planning tools discussed will be: COACH (Choosing Outcomes and Accommodations for Children), MAPS (Making Action Plans), PATH (Planning Alternative Tomorrows with Hope) and Circles of Friends. Michele Schneider, MS, Founder and Director of the Pound Ridge Learning Center in Pound Ridge, NY, Advocate, MS in Special Education, Orton-Gillingham Practitioner and Donna Franchini Sparago, Family Case Management, Case Management Supervisor, DMR Southwest Region. Sponsored by STEPS of Darien. Held at the Darien Library, 9:30 to 11:30, 35 Leroy Avenue, Darien. *To RSVP or to find out more about STEP's, please call the YWCA at (203) 655-2535 extension 61. You can also reach them at YWCASTEPSDarien@aol.com.*
- FEBRUARY 6: EXTENDED SCHOOL YEAR. Jose Centeno, State of Connecticut, Office of Protection and Advocacy for Persons with Disabilities. Seminar will focus on extended school year services. Also, the role of P & A will be explained, with their mission of citizenship, justice, and belonging. Held at Waveny House, Waveny Park, South Avenue, New Canaan, CT. Thursday, 10 to noon. Sponsored by SPED*NET New Canaan. *Please RSVP Anne at (203) 966-9709 or Beth at (203) 966-2982.*
- FEBRUARY 12: TRANSITIONING TO COLLEGE AND LIFE BEYOND HIGH SCHOOL FOR YOUNG ADULTS WITH SPECIAL NEEDS. Wednesday. 7:00 pm networking/refreshments, 7:30 pm program. Stamford Government Center, 888 Washington Blvd., 5th floor board room. *Please bring picture ID for security checkpoint. Sponsored by SCOPES. www.scopesnetwork.org.*

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.

A Successful 2002 Convention!

The 17th annual CDSC Convention, entitled "Life as We Know It", was held Saturday, October 5th, at the Farmington Marriott. Approximately 260 persons got together for a day of education, inspiration, and fellowship. There were approximately 50 educators and other professionals attending. This was the first time that the convention, our biggest event of the year, was held at a professional conference facility.

The Keynote presenters CDSC's Ashley Wolfe and Prof. Michael Bèrubè were very well received. As always, the accomplished Ashley wowed everyone, both as an inspiration for parents, and living proof to other newcomers of what a person with DS can achieve in life. The engaging Prof. Bèrubè presented a mix of personal experiences with his son Jamie, a person with DS, woven in with his heartfelt observation and commentary on "capability" rights.

Another first this year was the musical entertainment provided by Sujeet Desai. Suj, a young man with Down syndrome, is an accomplished musician who plays piano, violin, and clarinet. Suj provided inspiration and a classy feel to the convention. He also got rave reviews.

We had twenty quality workshops geared to parents, professionals, and teens/young adults. A wide variety of subject matter was presented by many caring professionals. There were a few workshops facilitated by several CDSC members, giving a warm, supportive, personal feel to the parents of newborns, and others new to the convention and CDSC.

Seventy-three surveys, and countless other responses were received. Overall, we got very high marks, both from parents and the large number of teachers/professionals in attendance! We think it is important to build on this, and continuously strive to improve.

Thank you to all that attended, participated, and otherwise helped to make the 2002 CDSC Convention, "Life as We Know It", the major success that it was!

—Ken Cholewinski

CONGRATULATIONS TO THE WINNERS OF THE CONNECTICUT DOWN SYNDROME CONGRESS AWARDS!

Outstanding Person With Down Syndrome-Laura Mallin, Wethersfield

Outstanding Teacher-Heather Maccabe, Teaches at Wilton Montessori School in Wilton

Outstanding School-Sacred Heart, Groton

Outstanding Community Program-The Recreation Department at The Kennedy Center, Bridgeport

Outstanding Individual Service-Fran Kondziela, Fairfield

Attention Parents/Guardians of Children in Wethersfield's Special Education Program

Wethersfield Special Kids is a not-for-profit support group for parents/guardians, family members, educators, and professionals who have children or who are associated with children in Wethersfield's Special Education program. The group meets monthly with meetings alternating between informal and open-ended discussions on topics chosen by parents, and guest speakers chosen to speak about a specific topic of interest to the group. Meetings are held on the second Wednesday of the month at 6:30PM in the cafeteria at the Webb building.

The following is a schedule of upcoming meetings.

December 11, 2002

January 8, 2003

February 12, 2003

March 12, 2003

The purpose of the group is to help everyone involved with children with special education needs get information and knowledge so that they will be in a position to ensure those children receive the best education available. Anyone with questions or needing more information can contact Patti Silva at 860-529-7766.

Commonly Asked Questions and Answers About Adapting Curriculum and Instruction

From “Adapting Curriculum and Instruction in Inclusive Classrooms: A Teacher’s Desk Reference,” by Deschenes, Ebeling, and Sprague.

Q. Are adaptations just for students with identified disabilities?

A. Adaptations are necessary and appropriate for any student who is not experiencing success, regardless of whether that student has a disability. Research and educational values tell us that all children can learn what is important for them to learn, and that the teacher's role is to assist all students to succeed.

Q. What areas of the curriculum or aspects of instruction can be adapted?

A. The three areas that teachers typically adapt are curriculum materials (e.g., textbook assignments, workbook or worksheet pages, and tests), instruction (e.g., grouping strategies, learning centers, audio visuals, and cooperative learning), and classroom organization and behavior management (e.g., daily schedule and routines, classroom rules, seating arrangements, and individualized behavior plans). When planning adaptations, consider all possible areas and, if necessary, adapt in more than one area at a time.

Q. Will teachers have to create completely different lesson plans for different students? How much extra planning time will this take?

A. Adaptations for individual students are based on the same lessons that are planned for the whole class. There is no need to create different lesson plans since the goal of adaptation is to make typical lessons more accessible to all. The needs of each individual student will dictate the extent to which lessons must be adapted. Types of adaptations will vary greatly depending on individual student needs and instructional goals. Many teachers report that the more experience they gain in adapting, the less time it takes to plan adaptations. Teachers also suggest that the adaptation process itself becomes automatic or intuitive over time, requiring no extra planning time.

Q. How intrusive should adaptations be?

A. As adaptations are generated, a continuum of intrusiveness will become apparent. Some adaptations will closely resemble the activities of classmates, while others will be less similar and require alternate materials,

supports, or types of instruction. To create “least intrusive curriculum and instruction,” it is often beneficial to begin with less intrusive adaptations and work up as necessary. In addition, when adaptations are necessary, it is important to minimize rather than highlight student differences. For example, a communication notebook that hangs around a student's neck will be stigmatizing. By contrast, a small billfold-sized notebook will meet the same goal without calling unnecessary attention to the differences between students. Progress monitoring is also important so that adaptations can be made less intrusive as students gain skills and competencies.

Q. Who is responsible for identifying educational goals for students with disabilities in an inclusive classroom?

A. The special education case conference committee, including teachers from general and special education, related services staff, parents, and others are responsible for identifying goals and objectives for students with disabilities. This team will also identify adaptations that will be necessary in order for students to meet those goals. These adaptations are documented on the student’s IEP. These adaptations typically include those needed across settings and times of the day (e.g., seating arrangement, adaptive equipment, augmentative communication system, behavior plans, mobility aids).

Q. Who is responsible for creating adaptations on a day to day basis?

A. Creating and implementing adaptations is the responsibility of all who provide instruction for a student (e.g., teachers, teaching assistants, peers, behavior specialists, related services staff, principals, and general education intervention teams). These teams, sometimes called student support teams, are small groups that meet on a regular basis (often once per week in the beginning fading to twice per month) to plan daily adaptations, problem solve, and assist in evaluating student progress. In addition to formal teaming, informal communication (e.g., logs, forms, lunchroom chats) between teachers and others is essential.

Q. Won't adapting curriculum and instruction create lowered expectations and watered down curriculum for all?

A. There is no evidence that students in classrooms where adaptations regularly occur score differently than their peers on achievement or other benchmark tests. In contrast, many teachers observe higher levels of mastery for nondisabled students when adaptations are common practice. Since adaptations are made for students at the

story continued next page...

Commonly Asked Questions and Answers About Adapting Curriculum and Instruction...continued

high end of the achievement continuum as well as at the lower end, there is no need to make significant adjustments in the typical pace of instruction for the majority of students. As teachers make adaptations, they evaluate each student's abilities and determine the minimal amount of adaptation needed in order for that student to succeed. In many cases this means increased rather than lowered expectations.

Q. *Is it really fair and equitable to adapt for individual students? Won't students resent their classmates who have adaptations made for them?*

A. Though a common concern for many teachers, the problem of fairness appears to be more of an issue for adults than for students. In a recent interview in an elementary school where adaptation is the norm, a group of nondisabled students were asked if they felt it was fair for classmates to receive adapted assignments and tests. Overall students responded that it was fair because everyone is different. Student comments included: "It's okay because they're getting better," "Shorter assignments don't bother me because they need more help than I do," and "It makes me feel good that the teacher helps them." Making adaptations available to any student who needs them, and creating a classroom climate of acceptance, often minimizes the problem.

THE UNIVERSITY OF CONNECTICUT A.J. PAPPANIKOU CENTER FOR DEVELOPMENTAL

DISABILITIES *has received a grant involving toddlers and infants and important issues regarding their development and access to childcare.*

The project involves working to include children who have complex medical needs into community-based childcare. This grant is funded through the U.S. Department of Health and Human Services, Administration for Children and Families. The project is called "Child Care for Children with Complex Medical Needs and Disabilities: Linking the Medical Home". We are looking for families with children ages birth to three who would like to access childcare and give their child a chance to socialize with other children. We will assist and train childcare providers to work as partners with parents, medical providers, and early intervention specialists to meet each child's unique medical needs in the childcare setting.

We have availability for 8 more children this year, and we will open the availability to 10 more children in the beginning of 2003. For more information about this project or information on how to participate, please call Erin Barnes at (860) 679-1559 or Michelle T. Kinsella at (860) 679-1532.

"Get Your Smiles"

CDSC is proud to introduce our 2003 Delightful Smiles Calendar.

The calendar features gorgeous photos of children throughout Connecticut.

All proceeds benefit the CDSC. A perfect gift for relatives, teachers, therapists, etc.

Limited supply.

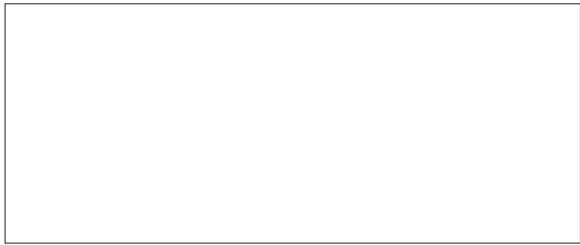
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Child's Name	Date of Birth	Has D.S.?
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____
5. _____	_____	_____

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.