

A Special Thank You

In October of 2002 my friend Carl Raynard and I, Mark Van Schelt, with our parents and my sister Amy went on an adventure to England. We were going to a Down Syndrome Invitational swim meet in Reading England. It was the first time Carl and I had ever been out of the country and so we had to have passports and even get some English pounds.

We had a few free days before the meet which we spent sightseeing. One day we went to London and had a ride on the London Eye. That is like a large ferris wheel only a lot bigger. We also visited the House of Parliament and had a bus tour of the city of London. We didn't sit on the top of the bus because it was too cold outside. We did some sightseeing in Reading too. We visited an old abbey and had our picture taken with some Bobbies, who are policemen.

The time for the swim meet came along all too soon. There were swimmers from, England, Ireland, Finland, South Africa, China, India and us from the USA. There was also a boy from Utah there. Carl received a gold, two bronze and two fifth medals. I received a bronze and two fifth medals. The competition



Carl Raynard and Mark Van Schelt of Windsor Locks.

was very good, everyone did their best.

On the last day after the swimming was all over every one put on their best clothes and we went to a fancy hotel for a great evening of eating and dancing. I had a ball. I danced all night with my friends that I had made over the week. I had the best time with the group from Ireland who were staying, at the same hotel as we were. All in all we had a wonderful time and I want to thank your group for giving us your donation to help with the costs. There is going to be a second swim meet in 2004 in South Africa. I hope someone will be able to go there. Maybe it will be me.

Very truly yours,
 Mark Van Schelt

IN THIS ISSUE:

| | |
|---|---|
| Reading Instruction for Children with Intellectual Disabilities . . . | 2 |
| President's Message | 3 |
| Statewide Calendar of Events | 4 |
| The Florida Miracle Coming to Connecticut | 5 |
| Family Educational Rights and Privacy Act (FERPA): | 6 |
| Papanikou Center | 7 |

CONTACT INFORMATION

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

2003 BOARD OF DIRECTORS

| | |
|----------------------|------------------|
| President | Beth Lurie |
| Past President | David Mathis |
| Exec Vice President | Lynn Cholewinski |
| Secretary & Director | Chris McAuliffe |
| Treasurer & Director | Krista Dean |

COUNTY VICE PRESIDENTS & DIRECTORS

| | |
|-----------------------|--|
| Fairfield | Linda Paoletta Barbara Rossiello |
| Hartford East/Tolland | Diane Bailey Suellen Lavigne Debbie Keller |
| Hartford West | Patti Silva |
| Litchfield | Penny Infrerra, VP |
| Middlesex | Position Available |
| New Haven | Sue Campagna Duffy Mudry Pamela Wilson |
| New London | Position Available |
| Windam | Position Available |

AT-LARGE DIRECTORS

| | |
|--------------------------------|------------------------------|
| Larry Gray | Dr. Robert Greenstein |
| Jules Van Schelt | Marilyn Kitler |
| Catherine Klein | Ken Cholewinski |
| Ricky & Donna Milnarik | Kathi Reiss |
| Lisa Cassello | Patty Farrell |
| Kathy Lopes | Jeanne Picklesimer |
| Tom Smith | |
| Self-Advocate Administrator | Nicolle Geiling Joan Gray |

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.

READING INSTRUCTION FOR CHILDREN WITH INTELLECTUAL DISABILITIES

The University of Connecticut Center for Disabilities is submitting a grant proposal to the US Dept of Education to study reading instruction for children with Down syndrome and other intellectual disabilities. We are looking for 60 children with intellectual disabilities who will be entering first grade in Connecticut public schools in September 2003 to participate. Half of the children in the study (30) will receive specialized instruction in phonological awareness and the remaining 30 children will participate in the standard reading instruction in their school. In this way, we can compare the progress of the children receiving the specific phonological awareness training against children receiving standard instruction to determine if it is beneficial. Some recent studies have suggested that children with Down syndrome experience deficits in phonological awareness in much the same way as children with dyslexia. A definition of phonological awareness is included below. Parents of participating children would not know until the study had ended whether their child was in the control group (no intervention) or the group receiving intervention in phonological awareness. All parents would be provided with a copy of the results of the study, if desired.

We are trying to determine whether we would have enough eligible children to complete this study. If you believe you would be interested, please contact Kathy Whitbread at 860-679-1565 or by email at Whitbread@nso1.uhc.edu. You would not be making a commitment, only determining interest. Kathy is available to answer any questions regarding the study.

What Is Phonological Awareness?

Phonological awareness is the understanding of different ways that oral language can be divided into smaller components and manipulated. Spoken language can be broken down in many different ways, including sentences into words and words into syllables (e. g., in the word simple, "sim" and "ple"), onset and rime (e. g., in the word broom, "br" and "oom"), and individual phonemes (e.g., in the word hamper, "h", "a", "m", "p", "er"). Manipulating sounds includes deleting, adding, or substituting syllables or sounds (e.g., say can; say it without the "k"; say can with "m" instead of "k"). Being phonologically aware means having a general understanding at all of these levels.

President's Message

FEBRUARY 2003

Usually I take the blank page of this President's Message as a chance to write about what's on my mind with respect to my daughter with Down syndrome, Eve; her school and home life; or the parallel universe of advocacy for persons with disabilities. This month I have been procrastinating because what's on my mind lately is that Eve is having a tough time at school. On the surface, things are going well: she reads at her grade level, she enjoys learning and being at school, and the school is extremely supportive of Eve as she makes her way through first grade. Eve's problems are mostly of her own doing. She's a kid with a stubborn streak a mile wide (like her mother), a wariness of authority figures (like her father), and she's savvy enough to know how to manipulate the system to suit her needs. The school personnel call it, "willful noncompliance." Another description is, being a pain in the butt!

When I describe this situation to people who work in the field of disabilities, their reaction is the same: isn't it great that Eve has a strong personality—it'll help her get what she wants in life! Isn't it great that Eve can manipulate people—it shows a high level of social awareness! Isn't it great that Eve tells the teacher that she's not doing any work today—she has such wonderful expressive language skills! Yeah, but they don't have to live with her!

All kidding aside, the past few months have been trying for us as a family and for the teachers at her school. But it's given me a chance to reflect on a very important truth: Eve is her own person, with her own robust and well-developed personality; her temperament is not defined by the fact that she has some extra chromosomal matter. I have no doubt that she'd be a little troublemaker even without that stuff (just look at her little brother!) When Eve was just a few weeks old, Jay and I took her to meet a family that included a ten year old boy with Down syndrome. His mom said one thing that's stuck with me: "You know that stereotype, that people with Down syndrome are always happy and huggy? Well, that's not my Ian." And it's not Eve, either. She's stubborn because she's Eve, not because it's part of the package deal that comes with trisomy 21. Truth be told, she's going to have a tough time being so willful, because she's under the extra-strong microscope that does come with the diagnosis of Down syndrome. As her parent, I can try to teach her the critical life skill of flexibility (even as I learn it myself!); her teachers can too. But the rest will be up to Eve.

—Beth Lurie

WE NEED YOUR HELP WITH THE CDSC CORPORATE SPONSORSHIP INITIATIVE!

These past few years the CDSC has done many great new things that should continue, e.g. book donations to schools, medical conference, annual picnic, Libby Kumin educational conference, annual convention at a professional facility, website, many Mini-grants, etc. Because of these events and programs, the reputation of the CDSC has been enhanced to an extensive degree. Most are as good, or better, than those of many larger organizations, and we are often lauded for them.

To continue to produce these excellent quality programs and conferences in support of members and friends of persons with Down syndrome, the CDSC needs to further enhance its revenues. Therefore, we have started an initiative to identify and solicit contributors in a professional manner. We are aiming to establish ongoing relationships with sponsors, and publicize the CDSC name and purpose. The primary focus is corporate, professional, and other non-profit organizations, however, individual contributors are also greatly appreciated. In addition to helping our cause, corporate donors and individuals may benefit from this tax-deductible charitable contribution.

That's where the CDSC team effort comes in! Everyone is needed to help with launching CDSC's first fundraising initiative. We need your help by providing us with contact information for potential contributors to this worthy effort.

*For more details, or to forward contact information please call Jaye Carlson at
203-457-9505 or e-mail : jcarlson@robbinscompany.com .*

STATEWIDE CALENDAR OF EVENTS

for program details please visit www.spednet.org

MARCH 18: WRITTEN NOTICE FOR A "MOCK IEP MEETING."
GIVING CONSENT TO EVALUATION: CONSIDERATIONS. Tuesday, March 18,
7:00-8:30 pm. The Rehab Center 26 Palmer's Hill Road, Stamford, CT.
For more information call ARC Parent to Parent at (203) 629 - 1880 ext. 300.

MARCH 18: THE EARLY DIAGNOSIS AND TREATMENT OF CHILDREN WITH
AUTISM SPECTRUM DISORDERS. Tuesday, 7:00 pm. Sponsored by Connecticut
Center for Child Development, 925 Bridgeport Avenue, Milford, CT 06460.
Call Holly Sickles to make reservations at (203) 882-8810, ext. 10. Due to space
limitations, please notify us of cancellations as early as possible.

MARCH 21: HOW OUR CHILDREN LEARN BEST—SUCCESSFULLY MODIFYING
CURRICULUM. Seminar will be held from 10:00 AM to 12:00 noon, at the
Wilton Library on 137 Old Ridgefield Road, in Wilton, CT. Please RSVP to
Heidi Von Hoffmann at 563-9090.

MARCH 21: THE FAIRFIELD SEPTA WILL BE HAVING A "NEW MOON AUCTION"
Friday night, 7-11 PM. Cost \$30 per person. Held at the Discovery Museum in
Bridgeport. Casual cocktail party. Please contact Wendy Anderson Brachfeld at
wendy@brachfeld.net or (203) 255-2520 if you would like more information.

MARCH 25: THE LOWER FAIRFIELD LOCAL INTERAGENCY COORDINATING
COUNCIL AND PARENT TO PARENT NETWORK IS PLEASED TO SEND YOU
WRITTEN PRIOR NOTICE FOR A "MOCK IEP MEETING." MOCK IEP
101. Tuesday, March 25, 7:00-8:30 pm. The Rehab Center 26 Palmer's Hill
Road Stamford, CT. For more information call: ARC Parent to Parent at
(203) 629-1880 ext. 100 or LICC Representative Beth Reagle at (203) 964-1143.

MARCH 27: THE NO CHILD LEFT BEHIND ACT'S IMPACT ON CHILDREN WITH
SPECIAL NEEDS OR LEARNING DISABILITIES. At 9:30 in the Weston Public
Library on Norfield Road in Weston. Speaker is special education attorney,
Howard Klebanoff. Please RSVP Karen Lindwall at 226-4741 or
zoe167@earthlink.net.

MARCH 29. MASSACHUSETTS DOWN SYNDROM CONGRESS ANNUAL
CONFERENCE. Worcester, Mass. For more info contact www.mdsc.org/conf03info.htm

MARCH 29 AND APRIL 25: U.S.E. (UNDERSTANDING SPECIAL EDUCATION)
COURSE ALONG WITH THE WORKSHOPS ON THE IEP TEAM AND INCLUSION.
Two Saturdays, 9:00-1:30 pm. Held at Ability Beyond Disability (formally
DATAHR), 135 Old State Road, Brookfield, CT. For more info, call Linda
Rietschel at WeCAHR (203) 762-3540. Funded by the CT Council on
Developmental Disabilities and sponsored by UConn.

MARCH 31, APRIL 1, APRIL 2: BANNER ELECTRICAL IS PROUD TO SPONSOR
WORKSHOP #1: INTRODUCTION TO VERBAL BEHAVIOR TEACHING COMMUNICATION
SKILLS TO CHILDREN WITH AUTISM AND OTHER DEVELOPMENTAL DISABILITIES.
Trumbull Marriott 180 Hawley Lane Trumbull CT 06611 Ph:(203) 378-1400.
Monday March 31st, Tuesday April 1st and Wednesday April 2nd from
8am-5pm each day. For more info, email banelec@hotmail.com.

APRIL 1: LYME DISEASE SUPPORT GROUP FOR TEENS. 4:30 pm, Comstock
Community Center, 180 School Road, Wilton, CT. (See March 12.)

APRIL 1: PIZZA MOMS IS A GROUP OF MOMS WITH SPECIAL NEEDS CHILDREN IN
THE FAIRFIELD COUNTY AREA. We meet the first Tuesday of every month at
7:30 pm in Darien at the Post Diner on Connecticut Avenue and Rt. 124.
If you are interested in coming please email Nanette at: Nanette618@yahoo.com

APRIL 2: THE CT BIRTH TO THREE LOWER FAIRFIELD INTERAGENCY
COORDINATING COUNCIL PRESENTS THE BIRTH TO SIX FOCUS GROUP FOR
PARENTS OF CHILDREN IN THE BIRTH TO THREE SYSTEM AND EARLY CHILDHOOD
SPECIAL EDUCATION. Meetings held at The Rehab Center at 26 Palmer's Hill
Road in Stamford on the following Wednesdays from 9:30 - 11:00 am: February
5, (topic - communication); April 2, (topic - behavior); and June 4, (topic -
play and toys). For more information, please call Beth Reagle at (203) 964-1143 or
Lolli Ross at (203)629-1880 x 132.

APRIL 7: TRANSITIONS: ELEMENTARY SCHOOL TO MIDDLE SCHOOL AND MIDDLE
SCHOOL TO HIGH SCHOOL AND BEYOND... Monday. Held at the Darien Library,
9:30-11:30, 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.

APRIL 8: ARC OF GREENWICH SPONSORS A MONTHLY SOCIAL GET-TOGETHER FOR
FATHERS OF SPECIAL NEEDS CHILDREN. Second Tuesday 7:30-9:30 pm at 132 East
Putnam Avenue, Cos Cob, CT. Call (203) 629-1880 x100. Or to join the
informational email list only, write to Specialdads-subscribe@yahoo.com.

APRIL 8: LEAVING BIRTH TO THREE WORKSHOPS Tuesday. 7:30 pm at
ARC Youth Division, 132 East Putnam Avenue, Cos Cob. In English. Contact
Ross@arcgreenwich.org for more info.

APRIL 9: SPOTLIGHT ON ASSISTIVE TECHNOLOGY. 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.

APRIL 9: LYME DISEASE SUPPORT GROUP. OPEN TO PATIENTS, FAMILY, AND
FRIENDS. 7:30-9:00 pm, Comstock Community Center, 180 School Road,
Wilton, CT. (See March 12.)

NOTE NEW DATE! APRIL 28: HOW CAN NEXT YEAR BE BETTER? Seminar will be
held from 10:00 am -12:00 noon, at the Wilton Library on 137 Old Ridgefield
Road, in Wilton, CT. Please RSVP to Heidi Von Hoffmann at 563-9090.

APRIL 17: INCREASING SPONTANEOUS LANGUAGE FOR CHILDREN WITH MORE
ADVANCED COMMUNICATION SKILLS. Thursday, 7:00 pm Sponsored by
Connecticut Center for Child Development, 925 Bridgeport Avenue, Milford,
CT 06460. Call Holly Sickles to make reservations at (203) 882-8810, ext 10.
Due to space limitations, please notify us of cancellations as early as possible.

APRIL 22: LEAVING BIRTH TO THREE WORKSHOPS Tuesday, 10:00 am
at The Rubino Center, 208 East Avenue, Norwalk. In English. Contact
Ross@arcgreenwich.org for more info.

APRIL 24: UNDERSTANDING THE TESTING INSTRUMENTS. Held at Waveny
House, Waveny Park, South Avenue, New Canaan, CT. Thursday, 10 to noon.
Please RSVP Anne at (203) 966-9709 or Beth at (203) 966-2982.

APRIL 24: AUDITORY PROCESSING DISORDERS. At 9:30 at the Weston Public
Library on Norfield Road in Weston. Please RSVP Karen Lindwall at 226-4741
or zoe167@earthlink.net.

APRIL 28, 29, MAY 5,6: THE PARENT TO PARENT NETWORK OF LOWER
FAIRFIELD COUNTY IS PLEASED TO OFFER THE U.S.E. (UNDERSTANDING SPECIAL
EDUCATION) COURSE ALONG WITH THE WORKSHOPS ON THE IEP TEAM AND
INCLUSION. Monday & Tuesday evenings, April 28 & 29 and May 5 & 6.
6:30 - 9:00 pm ARC Youth Division, 132 East Putnam Avenue, Cos Cob,
CT 06807 Questions? Please call Suzanne Ford at (203)629-1889 x100.

APRIL 29: TRANSITION LUNCHEON Tuesday, 11:45 - 1:00 at The Rehab
Center; 26 Palmer's Hill Road, Stamford. Contact: Debbie Nemchek 2034 x30.
Contact Ross@arcgreenwich.org for more info.

MAY 18, 2003 CDSC ANNUAL GOLF TOURNAMENT Twin Hills Country
Club, Coventry. For more information contact Bob or Kathi at (203)937-7931.

SEPTEMBER 13, 2003 NDSS CT BUDDY WALK

SATURDAY OCTOBER 11TH, 2003: SAVE THE DATE!

CDSC Convention 2003 Down Syndrome: Celebrate the Differences!
Farmington Marriott Hotel and Conference Center
More details to follow in next newsletter!

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.

“The Florida Miracle Coming to Connecticut”

by Lewis M. Andrews, Executive Director of the Yankee Institute for Public Policy, Hartford

For almost three years, parents of special education children in Florida have been given the option of receiving publicly funded vouchers to send their son or daughter to any school they wish, even if it is religious. The program has become so popular so fast that the idea is spreading rapidly to other states, including Connecticut.

In 1999, a voucher program adopted by the Florida legislature authorized a pilot program for students with learning disabilities in Sarasota County. Under this test project, the only requirement for a child receiving special education services to transfer to a private school, was that his parents express dissatisfaction over his progress at meeting the goals of his individualized instructional plan.

So popular was the pilot program that just one year later state senator John McKay was able to pass an amendment to the original law, allowing the Sarasota County provision to apply to the entire state. According to the new law, known as the McKay Scholarship Program, private schools taking on a child with special needs could recover from the government between \$6,000 and \$20,000, depending on the severity of the child's disability. The only caveat was that any school wanting to participate in the program had to accept all learning disabled applicants.

In the school year 2000-2001, 105 private schools in thirty-six of Florida's sixty-seven districts signed up to enroll more than 900 special education students. For the school year 2001-2002, Florida state officials estimate the number of special education students receiving assistance quadrupled to 4,000, while the number of participating schools tripled to over 300. For the coming academic year (2002-2003), the state of Florida has already received more than 25,000 applicants, making the McKay Scholarship Program the largest education voucher program of any kind in the United States.

Although researchers have yet to identify the precise reasons why the expansion of the McKay Scholarship Program had such easy political sailing, anecdotal evidence suggests strong backing from the largest group of eligible families—those with moderately disabled children who, while continuing to be promoted with their classmates, were nevertheless floundering academically. “My child needed a choice, an alternative. (She) was lost in middle school,” says the mother of a scholarship recipient. “She was held back early on, and the district did not want to keep holding her back, so even though she was not learning, she was moved along.” Black clergy from Florida's cities, where the percentage of fourth graders unable to read can soar as high as sixty percent, were also outspoken advocates of the McKay Scholarship Program.

The good news for parents of special education kids in Connecticut is that a number of groups and individuals in our state have formed a coalition—Families Allied for Choice in Education (FACE)—to design and promote our own version of the McKay Scholarship Program. While wanting to maintain the spirit and basic structure of the Florida legislation, FACE members recognize that Connecticut is a unique state with its own needs and requirements. Given the high cost of education in our state, for example, it is likely that the range of the McKay Scholarships (\$6,000 to \$20,000) would have to be raised considerably.

FACE is eager to have both the participation of, and feedback from, parents of special education children from across the state. FACE also wants to educate as many parents as possible about the benefits of the McKay Scholarship Program to Florida's learning disabled children and how a similar bill could work here in Connecticut. Those who would like to learn more are encouraged to call the Family Institute at 860-548-0066.

Commentary from Beth Lurie, CDSC President:

The issue of school vouchers as it pertains to students receiving special education services is a complex one.

A few important questions to keep in mind are:

1. Are the vouchers enough to cover the entire costs of a private education? Does the child still need to meet entrance/eligibility requirements? Who are the children being left behind at the public school: are they primarily poor and/or receive special education services?
2. There is a concern that those towns who currently include children with special needs well could be flooded by this process, and the quality of their inclusion would suffer. Secondly, the process seems to attempt to supercede the IDEA and PPT process. Rather than building good programs in all communities, will we give towns that don't include kids with disabilities an incentive not to even try? It could defeat the concept of developing welcoming communities in all towns.
3. Is there any outcome data from Florida? What was the impact on existing quality special education programs and how was that quality measured? How was parental and child satisfaction measured? What impact did it have on inclusion in all communities?

FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT (FERPA):

What is it and what does it mean to my child?

1. WHAT IS FERPA?

The Family Educational Rights and Privacy Act (FERPA) is a Federal law that protects the privacy of student education records. The law applies to all public schools. FERPA gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level.

Parents have the right to inspect and review the student's education records maintained by the school. Schools are not required to provide copies of records unless, for reasons such as great distance, it is impossible for parents or eligible students to review the records. Schools may charge a fee for copies.

Parents have the right to request that a school correct records that they believe to be inaccurate or misleading. If the school decides not to amend the record, the parent then has the right to a formal hearing. After the hearing, if the school still decides not to amend the record, the parent has the right to place a statement with the record setting forth his or her view about the contested information.

Generally, schools must have written permission from the parent in order to release any information from a student's education record. However, FERPA allows schools to disclose those records, without consent, to the following parties or under the following conditions:

- School officials with legitimate educational interest;
- Other schools to which a student is transferring;
- Specified officials for audit or evaluation purposes;
- Appropriate parties in connection with financial aid to a student;
- Organizations conducting certain studies for or on behalf of the school;
- Accrediting organizations;
- To comply with a judicial order or lawfully issued subpoena;
- Appropriate officials in cases of health and safety emergencies; and
- State and local authorities, within a juvenile justice system, pursuant to specific State law.

2. WHAT RECORDS SHOULD I GET FROM MY CHILD'S SCHOOL, AND WHAT SHOULD I DO WITH THEM?

The files that your child's school maintains are a "cumulative file," a "confidential file," and possibly a "compliance file." Each school district may put different items in different folders, so it's important to ask for everything. The cumulative file often consists of personal identification data, some teacher reports, and report cards. The confidential file includes all of the reports written as a result of the school's evaluations, reports of any independent evaluations, medical records that you have released to the school, your child's IEP, and correspondence between you and the school. The compliance file may contain some of these items, and also anything else that might be used by the school to show that it has complied with timeline, notification, and consent regulations under IDEA. Your

school may also keep a separate file for discipline issues. Excluded from the records that schools must show you are teacher's notes, made for their own personal use and shown to no one else.

Every year it is important to get a complete copy of your child's records. You should review them to make sure that they are accurate, complete, free of bias, nonjudgmental, and consistent with your own assessment of your child. If left unchallenged, this material could lead to decisions about your child's educational placement that are not in his/her best interest. If you find a record that you believe is incorrect or deficient in some way, you can first try the informal path to changing it. You can ask the school principal or director of special education to remove the material, giving your reasons for the request, in writing. If they refuse, you can request a FERPA hearing, which must be held within a reasonable period of time. The purpose of the hearing is to allow you and the school system to present evidence about the school record in dispute and to let a hearing officer determine who is right. Even if you are ultimately denied a request to have a record removed, you can amend your child's record by writing a detailed explanation of your objections, describing why you believe the material is inaccurate, biased, incomplete, or otherwise inappropriate. The school is legally obligated to keep your statement with the record.

3. HOW ABOUT SOME HELP TO GET ME STARTED?

Following is a sample letter that you can mail to your school.

To: Ms. XX, School Psychologist
Pokey Oaks Elementary School
New Conundrum, CT 06543

January 31, 2003

Re: FERPA Request for all of Ivy Smith's records

In preparation for Ivy's upcoming IEP, I am requesting a copy of all of Ivy's records since November 8, 2001. Please include all of her records, which include but are not limited to: her cumulative file, her confidential file, and her compliance file. Please include all reports written as a result of the school's evaluations; reports of independent evaluations; medical records; summary reports of evaluation team and eligibility committee meetings; IEP's; any correspondence retained between myself and the school officials; any correspondence written between school personnel regarding my daughter; any records maintained by the school nurse, Ivy's teachers, and any member of the PPT team; notes or letters written in connection with any planning or discussions, or any other matters in connection with my daughter Ivy Smith.

Thanks in advance for your cooperation.

Very truly yours,
Anne Smith
123 Main Street
New Conundrum, CT 06543
Tel: (203) 555-1234
Fax: (203) 555-5678
Smith99@aol.com

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

Childcare for Children with Complex Medical Needs: Linking the Medical Home

Many children under the age of three years attend childcare. Childcare offers multiple social opportunities for young children, in addition to providing the outside care families require. Families of children with complex medical needs are no different. However, in order for children with complex medical needs to successfully participate, childcare providers must feel confident and competent to meet both the care and developmental needs of the individual child. Families must also feel comfortable that their child's unique needs are being met and that the child is enjoying and participating in the developmental activities available throughout the day. The A.J. Papanikou Center for Developmental Disabilities can support families and childcare providers through the project "Childcare for Children with Complex Medical Needs: Linking the Medical Home." This project is designed to demonstrate the successful inclusion and accommodation of infants and toddlers with complex medical needs and disabilities into community-based childcare centers. Through this project, we support childcare providers in partnering with parents, medical providers, and early intervention specialists to effectively care for children with

complex medical needs. We are looking for families with infants or toddlers with complex medical needs who are interested in enrolling their children in childcare and would like support in making it a successful experience. For more information, please contact Dana Abbott at (860) 679-1500 or e-mail: dabbott@uchc.edu.

Connecticut Partners in Policymaking

Connecticut Partners in Policymaking, a training program of the University of Connecticut A.J. Papanikou Center for Developmental Disabilities and the Office of Protection & Advocacy for Persons with Disabilities, is now accepting applications for its class of 2003. This training is open to parents of children with disabilities and adults or teenagers with disabilities who want to increase their skills in leadership and advocacy. The course involves a 7-month commitment and is offered free of charge. For more information about the program or to download copies of the program brochure and application form, please visit www.uconned.org/partners/parthome.htm. For questions, please contact Molly Cole or Heather Harrison at (860) 679-1500. Partners in Policymaking is funded by The Connecticut Council on Developmental Disabilities

The Top 10 Characteristics of Responsible Inclusive Practices

Adapted with permission from Stetson and Associates, Inc.

1. Each student is educated in his or her neighborhood school.
2. There is a natural proportion of students with disabilities at each school.
3. The faculty believes inclusion is a valued practice for all students.
4. The general education class and curriculum is the reference point for all instructional planning.
5. Students are in age appropriate general education classrooms.
6. Students are considered members of their general education homerooms.
7. An array of instructional strategies for diverse learners is used effectively in each classroom.
8. Special education support is provided for students with disabilities in the general education classroom when it is needed.
9. Special education and support services personnel are on grade level or subject area teams with their fellow general education teachers.
10. All educators regularly plan together to meet the needs of the students they serve.



CONNECTICUT
down syndrome
 CONGRESS

A PUBLICATION OF THE CONNECTICUT DOWN SYNDROME CONGRESS, INC.
 P.O. Box 340385, HARTFORD, CT 06134-0385

NON-PROFIT ORG.

U.S. POSTAGE
PAID

PERMIT #162
 HARTFORD, CT



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)
- 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.