

What is PATH Parent to Parent of CT?

We are a statewide, parent-to-parent support and information network created by families and for families of children with developmental and health related needs, families with life-long disabilities and for parents challenged with high-risk pregnancies and the critical effects of a baby born prematurely. Parents who have faced the unfathomable sadness of losing a child are also a part of the PATH network. We link newly referred parents with supporting parents who have had similar needs and experiences. We believe that parent- to-parent support is the cornerstone of family support and increases a parent's ability to cope and build hope for their child and family's future.

PATH PARENT TO PARENT OFFERS A WIDE RANGE OF RESOURCES FOR PARENTS SUCH AS;

- One to One matches of families who have similar needs and experiences
- Emotional Support and understanding
- Information about developmental and health related issues
- Information on local, state and national resources for families of children with developmental and health related needs
- Training for parents who would like to be a support for other parents
- Speaker Programs
- Resource Publications
- Lending Libraries

PATH's Listener Program which provides the one-to-one connection of families new to having a children with special care needs with "veteran" families, "who have been there" as well as training for veteran parents is a unique service found no where else in Connecticut and is truly the "heart" of PATH Parent to Parent of CT. Through our Listener Program new parents are provided with emotional support as well as resources and critical information, which families say, can't seem to find elsewhere.

CDSC will be sponsoring a PATH Listener training on Monday, November 11 in Farmington at 6pm. Dinner will be provided. Please call Joan Gray to register at 888.486.8537

If you would like more information about PATH Parent to Parent of CT, please call Carmina Cirioli at 1-800-399-PATH or 203-459-4687.

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CONTACT INFORMATION

Call us toll free at
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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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CDSC Membership Drive

We know how much you love your CDSC membership. In case you've forgotten, as a CDSC member you get the benefit of:

- Annual convention, featuring nationally known keynote speakers, over 20 workshops, great food, and terrific door prizes.
- Annual summer picnic, including free cookout and entertainment for the whole family.
- Quarterly, quality newsletter with filler such as this.
- Parent/professional conferences with nationally known speakers, on such topics as "Medical Issues in the Year 2000" and "Language Skills for Inclusion".
- New parent information, including the video "Life with Down Syndrome".
- Mini-Grant Program: a CDSC member can sponsor a grant application for up to \$500 towards a program or project that benefits a person with Down syndrome.
- Local activities such as playgroups and Mom's Night Out.

Currently CDSC has about 350 members, and our newsletter goes out to over 650 mailboxes. But we want more! So CDSC is going on a full-fledged, down-and-dirty Membership Drive. Details will be in your renewal notice this fall. But if you can't wait to hear the details, it goes like this: If you are not yet a member, join up for a first year discounted rate! Or, if you are a renewing member, give the gift of membership to a new member at the discounted rate! Come on, sign up your child's teachers, therapists, hairdresser, and tarot card reader at the low low price, and know that you are supporting a great organization too!

Look for more details in your renewal notice this fall!

President's Message

AUGUST 2002

My husband Jay recently remarked to me that whenever he is in town with Eve, they get an awful lot of “Hi, Eve”s from people he doesn’t know. Everyone knows Eve, it seems. I never really thought about “community” before, what it means and why it’s such an important thing. Maybe I would come to value community anyway, even if I didn’t have a six-year-old daughter with Down syndrome. Maybe it’s a natural part of raising kids: before kids you have the mindset of a single person, making your way in the world for better or worse. Then you have a kid and are thrown into the overwhelming reality and newness of Being Responsible for Another Human Being’s Entire Life - you are now a Parent. After a few years, that kid gets old enough to start engaging in the world without Parent by her side, and Parent realizes that the world is not always as warm and cozy a place as home. On top of this, that kid may not be as well equipped to deal with the world as Parent might like, or the world might expect. Wow, then Parent starts worrying about the community!

What makes a community? Here’s one dictionary definition for “community:” an interacting population of various kinds of individuals in a common location. This is my favorite definition of the many listed because it specifies three important components. The obvious one is “in a common location:” most often we think of a community as a town or other geographically close region, though it often is associated with a building like a school or church. The other thing to love about this definition is “various kinds of individuals:” any parent of a child with Down syndrome can appreciate the value in saying out loud that variety is a good thing! Finally, the most important part of community is that it is an “interacting population.” Community is not some part of the population over there in the corner, leading their own lives separately from the rest of town/school/church/recreational activities. Community is interaction; it is on the same streets and in the same conversations and at the same parties and at the same workplaces.

Community is not only the fact that everyone knows Eve. It’s that the Girl Scout leader didn’t think twice before saying “Of course, we would love to have Eve join our troop!” And that the shoe salesman always teases Eve good-naturedly about her wide foot. And that without prompting, a friend at the sailing club asks, “Eve will do the Junior Sailing program, right?” And that Eve’s entire Sunday school class is given carpet squares to sit on during story time, because Eve is better able to pay attention if she has a clearly demarcated space. In the long run, we’ll know we’re part of a true community when Eve is an independent adult, living, working, playing, and interacting with various kinds of individuals, just like all the other twenty-somethings.

CDSC’s vision is “to improve the lives of persons with Down syndrome, and encourage the community-at-large to receive and embrace them.” How does CDSC encourage communities to embrace our children? In recent years, we have provided professional training to medical doctors and to educators. We hope to continue to organize parent/professional conferences in the future. In addition, we run public service announcements on local cable television channels (look for Chris Burke). Finally, through local and statewide events, we are an informal network for parents to share ideas about what’s working in their own communities. If you have an interesting story to tell about how you’ve encouraged your community to embrace your child, please share it with the rest of us! Drop me an email at lurie@optonline.net or call me at 203-966-2982.

—Beth Lurie

STATEWIDE CALENDAR OF EVENTS

- August 13: OVERVIEW OF DMR 5 YEAR PLAN, by Laura Nuss, Regional Director. Westport Library, Arnold Bernhard Plaza, Westport, CT. 7:00-9:00 pm. *To register or for more information please contact Kim Barry at 576-3660 or email at Kimberly.Barry@po.state.ct.us*
- September 12: DEPARTMENT OF MENTAL RETARDATION, FAMILY INFORMATION SESSION TRAINING FOR FAMILIES AND PARENTS, TEACHING STRATEGIES FOR TOILET TRAINING. By Sandy Librandi, BMPS and Julie Herring, Family Trainer. United Way of Stamford, 62 Palmers Hill Road, Stamford, CT, 9:30-11:30 am. *To register or for more information please contact Kim Barry at 576-3660 or email at Kimberly.Barry@po.state.ct.us*
- September 21 & 28: USE (UNDERSTANDING SPECIAL EDUCATION). The Parent to Parent Network of Lower Fairfield County is pleased to offer the U.S.E. course along with the workshops on The IEP Team and Inclusion. These workshops are offered at no cost to parents and professionals to learn more about special education. In order to register, you must attend both sessions. 9:00 am-4:00 pm. Held at The Rehab Center, 26 Palmer's Hill Road, Stamford. *Please call Ginger Spiers at (203) 846-1064.*
- September 24: REED MARTIN IS COMING TO CONNECTICUT!!! Sponsored by Parent to Parent of Greenwich ARC. Reed Martin is an attorney with over 33 years experience in special education law and recognized as one of the nation's leading experts. You can learn more about him at www.reedmartin.com. His mission is to lessen discrimination against children with disabilities by providing parents and school personnel tools for advocacy.
- October 3: MARYLAND COALITION FOR INCLUSIVE EDUCATION ANNUAL CONFERENCE. Sponsored by the Maryland State Department of Education Division of Special Education/Early Intervention Services in collaboration with the Maryland Coalition for Inclusive Education. A Conference on Inclusive Education. Baltimore Convention Center, One West Pratt Street, Baltimore, MD. *Check www.mcie.org for more info.*
- October 5: CT DOWN SYNDROME CONGRESS ANNUAL CONFERENCE. Held at the Marriott at Farmington, CT. *Check www.ctdownsyndrome.org for more information.*
- October 8, 15, 22, 29: USE (UNDERSTANDING SPECIAL EDUCATION). The Parent to Parent Network of Lower Fairfield County is pleased to offer the U.S.E. course along with the workshops on The IEP Team and Inclusion. These workshops are offered at no cost to parents and professionals to learn more about special education. In order to register, you must attend all sessions. Held at The Rehab Center, 26 Palmer's Hill Road, Stamford, CT 06902. *Please call Ginger Spiers at (203) 846-1064. Tuesday nights on Oct 8, 15, 22, & 29, 2002, 6:30-9pm.*
- October 12 & 19: USE (UNDERSTANDING SPECIAL EDUCATION). 9:00 am to 4:00 pm. STAR, Inc. – Lighting the Way... is pleased to offer the Understanding Special Education (U.S.E.) workshop along with a workshop on the Individualized Education Plan (IEP) and Inclusion. These workshops are offered free of charge to parents, advocates, and educators who want to be empowered with information on special education. Held at STAR, Inc – Lighting the Way..., 182 Wolfpit Ave., Norwalk . *Please call Linda Snell at STAR at (203) 846-9581 or e-mail her at lsnell@starinonline.com.*
- October 22: TOTAL TECHNOLOGY 2002 — CONNECTICUT'S PREMIER ASSISTIVE TECHNOLOGY TRADE SHOW. Looking for the latest devices that provide the link to independence and full participation in all life's activities? Talk to vendors, obtain loan information, attend a workshop or participate in a variety of sporting activities. Tuesday, October 22. Connecticut Expo Center, Hartford, CT, Free Parking and Admission. *For more information call 1-860-424-4871*
- December 11-14: TASH CONFERENCE, Boston, MA. 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. *Check www.tash.org for more info.*

CDSC Convention 2002

Saturday, October 5th.

KEYNOTE SPEAKERS: Michael Bérubé, noted professor of English Literature at Penn State University, literary critic, and author of several books, including "Life as We Know It" a chronicle of the first 4 years of life of his son Jamie, a person with DS, and of societal values and social justice. Also, CDSC's past college scholarship award winner Ashley Wolfe, an accomplished scholar and professional actor who is currently living the exciting single life in Boston.

THE CONVENTION COMMITTEE is busy with preparations for CDSC's biggest annual event. How can you help? We need as much input as possible in three areas:

1. Submit a photo of your child for inclusion in the convention brochure.
Please mail it to Ken Cholewinski at the address below. Digital photos can be emailed.
All photos will be returned.
2. What sort of workshops do you want to attend? Let us know your suggestions of topics and/or speakers!
3. Do you have a connection to a nonprofit or corporate organization that can help underwrite the cost of the convention? No donation is too small!

Convention committee chair Ken Cholewinski can be reached at KenCholewinski@aol.com, 47 Fawn Hill Rd., Killingworth, CT 06419, 860-663-2676. Thanks for your support!

Annual Golf Event a Success!



Kyle – Outback Steakhouse, Manchester.

The 12th annual CDSC golf tournament was held on May 21st at Twin Hills Country Club in Coventry. It was a day of great golfing, with great weather followed by a great meal generously donated by Outback Steakhouse of Manchester.

Thank you to the many people who make this day possible... whether a participant, some of whom have been playing in this tournament since it started 12 years ago, a sponsor or a volunteer, your contribution to the tournament is greatly appreciated. The CDSC thanks you for your support.

CONNECTICUT RESOURCES

A.J. Pappanikou Center for Developmental Disabilities

UNDERSTANDING SPECIAL EDUCATION (USE) is the updated version of the original Action Planning in Education or APLE course, which has successfully taught over 500 parents and professionals in Connecticut to advocate for effective educational programs for students with disabilities. APLE and USE, which stress the importance of parent-professional collaboration, were developed by the Parent Educational Advocacy Center in Virginia.

The 10-hour USE curriculum focuses on understanding the special education system, including eligibility, program development, placement, due process, inclusion, and individualized education plans (IEPs). The overall goal of the training is to improve the outcomes of special education for students with disabilities.

This training is a collaboration of the A.J. Pappanikou Center for Developmental Disabilities and ten private, non-profit agencies serving people with disabilities and is funded by a grant from the Connecticut Council on Developmental Disabilities.

For more information on the training or to find out if training is available near you, please visit www.uconned.org/use/usehome.htm or contact Anne Marie Davidson at (860) 679-1568 or e-mail: adavidson@up.uchc.edu or contact Gretchen Mueller Burke at (860) 679-1537 or e-mail: gburke@uchc.edu.

Project Recruitment

THE CHILDCARE FOR CHILDREN WITH COMPLEX MEDICAL NEEDS: LINKING THE MEDICAL HOME 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. The goal is to include childcare providers in the medical home so they can serve as partners with parents, medical providers, and early intervention specialists. We are looking for families with an infant or toddler with complex medical needs who would like childcare and an opportunity to promote their child's socialization.

For more information, please contact Andrea Garewski at (860) 679-1539 or e-mail: garewski@uchc.edu.

This is a project of the A.J. Pappanikou Center for Developmental Disabilities and is funded through a grant from the U.S. Department of Health and Human Services, Administration for Children and Families.

Family Voices of Connecticut Hosts Leadership Development Conference

Family Voices of Connecticut, in collaboration with the Family Voices New England Region, is hosting a Leadership Development Conference on October 14-17, 2002, at the Hole in the Wall Gang Camp in Ashford, Connecticut. Family Voices of Connecticut will be selecting ten parents of children with special health care needs to participate in the conference entitled "Building Leaders for Healthy Families 2010."

Each of the six New England states will select 10 families to attend the two-day meeting featuring national speakers from Family Voices, Maternal and Child Health, and the Academy of Pediatrics, as well as representatives from state health departments.

There is no charge for this two-day conference.

Interested family members can contact Molly Cole, state coordinator for Family Voices of Connecticut, for a family nomination form at (860) 679-1504. The Family Voices of Connecticut Board of Directors will make the final selection of parent participants in August 2002.

Book Program

Connecticut Down Syndrome Congress would like to donate books to your elementary school library. Some of the titles include, *Russ and the Firehouse*, *Russ and the Apple Tree Surprise*, and *We'll Paint the Octopus Red*, for the elementary school level. For the preschool level, we have *123 for You and Me*, and *ABC for You and Me*. Please keep in mind we have a limited supply. *If you are interested please call Penny Inferrera at 860-210-0048.*

Litchfield County News

Playgroup for ages five and under, is the second Saturday of every month. Parent night out Wednesday, August 24, 2002, at Aspen Garden Restaurant, Litchfield, CT.

*For more information,
please call Penny at 860-210-0048.*

