

Hudson Valley Connections

Parent to Parent of New York State

Fall 2006

Vol. 8

Contacts:

Parent-to-Parent NYS
Hudson Valley Region
The Family Connection
333 Cedarwood Hall
20 Hospital Oval
Valhalla, NY 10595
914-493-2635 or 1343
914-493-8066-fax
800-305-8816
E-mail: jstack@wihd.org

Satellite Office
Parent to Parent NYS
Taconic DDSO
26 Center Circle Bldg 58
Wassaic, NY 12592
845-877-6821 ext. 3927
845-877-1258 fax
E-mail: P2PCares@aol.com

**PTPNYS Hudson Valley
Regional Coordinator:**
Laura Carfi

Parent Coordinators:
Jackie Stack

**The Family Connection
Program Advisor:**
Barbara Levitz
(914) 493-2739
E-mail: blevitz@wihd.org
Websites
www.parenttoparentnys.org
www.wihd.org

From The Coordinators: *Laura Carfi and Jackie Stack*

Back to School

By now most of us are settling into the back to school routine. This time of year can be very exciting, busy and stressful all at the same time. For some of us the start of the new school year means new IEP's, transitions issues, therapy schedules, inclusion team meetings and transportation issues, just to name a few. One of the best ways we have found to address these and other issues we face is to ask other parents how they do it. Parents have a wealth of untapped knowledge. Do you have any questions or ideas that have worked for you in the past and would you like to share them with others? We are going to start a column in the Hudson Valley Connections newsletter called "Worked For Me". We are asking parents to share their questions and ideas about dealing with everyday life in raising a child with special needs. For example, one of our parents on staff has a problem with her 11-year-old daughter getting out of her seatbelt in the car. She's tried different car seats and looked for some kind of cover for the seat belt latch, but has had no luck. If anyone has any ideas that worked for them we would love to know about it. Please email any ideas about this month's question and any questions you have to jstack@wihd.org and we will include them in the next newsletter.

On Line Support Parent Training:

If you are interested in becoming a support parent on our network, you can now do the training on line. Go to www.parenttoparentnys.org and click on support parent training link. This offers families the flexibility to do the training at their own convenience and pace. You must fill out a support parent questionnaire, which can be submitted on line or you, can contact your local coordinator to receive one in the mail. This must be filled out entirely before you can do the training. Join our network and help make a difference in the lives of other families. Please call us with any questions. There is also an on-line training for a parent willing to be A Health Care Resource Parent. Check the website or contact Laura Carfi.

If you previously volunteered to be a support parent but have not yet completed the training and submitted the accompanying support parent questionnaire, this would be an excellent way to finalize your recruitment and training.

Family to Family Health Information Center:

Just a reminder that material for families related to health issues has been developed and is available in two ways. You can go on the Parent to Parent NYS website www.parenttoparentnys.org and click on Family to Family or we can send you a copy in the mail. Contact your local coordinator if interested.

Materials that are available include Medicaid Fact Sheets, Health Care Notebooks, Tips For Handling Medical Appointments, Financial Aid For Children With Special Health Care Needs, Record Keeping Tips, HCBS Waiver In NYS, Section 504 Accommodations, Coping and Stress Reduction Facts and Tips, Healthcare Information On The Internet, Medicaid Prescription Tips for Parents/Caregivers, Understanding Health Insurance and Doctor Selection Fact Sheet.

Parent-to-Parent has an e-group for parents who have children who are medically fragile or have complex medical needs. Email RR815@aol.com or visit the Parent-to-Parent NYS website listed above.

Family/Student Transition Update:

Depending on the age of your child, “transition” can mean different things. The one common feature is that each new transition will involve new organizations, new procedures, and new regulations to learn to navigate. The first transition a family typically experiences is from the Early Intervention Program to preschool. In the first program, parents work with the Department of Health. In the second, they work with an entirely new set of people: the Committee on Preschool Special Education (CPSE).

Next, a child transitions from preschool to the school system. During this transition, families once again encounter a new group of professionals and a new system: the Committee on Special Education (CSE).

When a child reaches 14, he or she enters another transitional period as they prepare to live, learn, and earn a living in the community as adults. Families have to think about and create transition goals in the IEP.

It is very confusing for a parent to get to know each new system and the “players” within. However, under the auspices of VESID (Vocational and Educational Services for Students with Disabilities) there is the Lifelong Service Network, which includes the Early Childhood Direction Center (ECDC)(birth through 5) and SETRC (Special Education Training and Resource Centers)(ages 5 through 21). The network is there to help families navigate the systems of services and supports across all age groups. Each year the network develops a theme, and this year’s theme is “Connections” which is also the mission of “Parent to Parent”.

“Parent to Parent” provides information and referral, trainings and, via the family matching program, a connection to others who have “been there.” As children go through different transitions from birth to adulthood, the support of others can be invaluable. Through Parent-to-Parent, we hope to be able to reach and help - more families at every stage of transition. Working together we can address issues including healthcare, education, and community services and supports.

As a parent of a young adult with cerebral palsy, I have sometimes felt that no one in my community in Westchester was experiencing what I was. Transitions were difficult and heart wrenching at times. Being part of Parent-to-Parent opened up new windows for me through which I learned of camps, respite, educational programs and eventually a wonderful residential facility for my son and I got connected to families who were there for me.

Please help us reach out to other families with children with disabilities and encourage them to be part of our Parent-to-Parent family. Once we are all a part of the Network, we can work more effectively towards improving the quality of life for people with disabilities and their families.

Diane Greble
S. Westchester BOCES Transition Coordination Site
Family/Student Specialist, 914-493-1027

RESOURCE GUIDE FOR FAMILIES:

A Guide to understanding supports and services administered through NYS Office of Mental Retardation and Developmental Disabilities.

This guide will prove to be a valuable tool for people with disabilities, parents, and caregivers. Copies of the guide can be downloaded from the Health Care Information and Education section of the Parent to Parent NYS website at www.parenttoparentnys.org

PARC'S RESPITE PROGRAM:

The respite assistance includes recruiting qualified sitters and providing them with training, paying for sitter services for up to twenty-two hours per month and coordinating with local hotels that donate a room one night every month at their facilities to a family. The Respite Program serves individuals of all ages and the only requirements are that the individual meet eligibility requirements for OMRDD and reside at home with their families.

Contact Elizabeth Hurley @ 845-278 PARC ext. 259

Family Support Position

Announced: Westchester Medical Center has posted a full time position as Director of Family Support Services and the Family Resource Center at the Children's Hospital. It would be a true asset to have a parent of a child with special needs in this. Mail, fax or email a resume to Alice McCluskey, Human resources, Elmwood Hall, Valhalla, NY 10595. Fax: (914) 493-8637. Email: mccluskey@wcmc.com.

Director of Family Support and the Family Resource Center - Maria Fareri Children's Hospital at Westchester Medical Center - is responsible for the design and implementation of programs and support systems for pediatric patients and their families served at Maria Fareri Children's Hospital at Westchester Medical Center, including the management of the Children's Hospital Family Resource Center and closely collaborates with several departments and divisions, including the volunteer department and child life. The Director will provide leadership in the practice of family-centered care for all care-giving, support and administrative staff and work with the team in developing structures and systems to support family-centered care.

Beach Center on Families and Disability:

www.beachcenter.org

The Beach Center invites you to participate in their on-line discussion on Self Determination Funding <http://beachcenter.org/wb/index/.asp>. Most important check out and sign on to the New National Consensus Statement on Family Support <http://www.beachcenter.org/default.asp?act=consensus>. Family support is once again a focus of national advocacy and each of us can participate and strengthen this initiative.

Down Syndrome Resource Center:

The Down Syndrome Resource Center (DSRC) is growing rapidly. In 2005 the DSRC provided information and support to families and professionals through seminars, creative programs, and personal contact. For more information, you can contact them at 518-391-2581

E-mail: info@downsyndromeresourcecenter.org

Website: www.downsyndromeresourcecenter.org

Hudson Valley News E-Group:

If you are interested in joining the e-group, please submit your name to P2PCares@aol.com. Your name will be added and you will receive information of special interest including news releases, events, forums, and workshops in the Hudson Valley area.

PTPNYS On-Line Training Center:

Training is offered to families on the following topics: Advocacy Skills and Techniques, Home Medical Care, 504 Accommodations, Parent/Professional Collaboration, Health Care Legal Rights, Health Care Record Keeping, Health Care Financial Resources. Check out the website: www.parenttoparentnys.org/onlinetrainingcenter.htm

Bilingual Parents Needed:

The HV Regional Office of PTPNYS is seeking bilingual Spanish-speaking parents of children with special health care needs in the Westchester area for a few hours a week as staff or volunteers for our Parent to Parent Hospital Visiting Program at the Children's Hospital. Contact Jackie Stack for more information.

Help Us Spread the Word about Parent to Parent:

Help us inform other parents and professional in the Hudson Valley Region about the availability of the parent-to-parent program as an important resource for families. Parent coordinators are available for presentations to parent groups, disability organizations and at community resource fairs. We can also provide brief articles about the program to have included in newsletters and directories. Contact Laura Carfi if you have ideas, suggestions. and potential contacts.

Families As Faculty:

If you are interested in joining our network of families involved in mentoring and training graduate students, medical students and pediatric residents, contact Barbara Levitz at blevitz@wihd.org. Watch for more information in the next issue of Hudson Valley Connections.

