



The **STAR**

SOUTHERN TIER AREA RESOURCES



Newsletter for the Southern Tier Region—Serving Chemung, Schuylers, Seneca and Steuben Counties

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Connecting and Supporting Families of Individuals with Special Needs www.parenttoparentnys.org

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Fall into Training!

The new school year is under way, the leaves are beginning to change and the geese are heading south. Why not follow the kids and fall into learning yourself by attending a workshop or trying an online training. You can browse our online trainings available at our state website: www.parenttoparentnys.org/onlinetrainingcenter.htm Be sure to check out our Parent Tools too: www.parenttoparentnys.org/Library/Parent%20Tools/tools.html



Happy New School Year! Well, the new school year has begun pretty successfully in our house. How about in yours? The anticipation of the new year can be wonderful or it can bring all sorts of anxiety. One thing that has worked for our family is to help both sides get to know each other ahead of time—my older son and his teachers. This helps alleviate some of the anxiety and tension during the beginning of the year. It also helps to build on their relationship by knowing a little bit about each other early on. Even though the school year is underway, it is not too late to help your child and his/her teachers have a better relationship. Consider some of the suggestions offered at the sites below:

15 Things About Me: <http://www.nlconcepts.com/autism-teacherletter.htm> (you have to sign-in your email to receive it; but it is free. This is primarily for children with autism; but still a good idea for anyone.)

Assemble a Teacher packet: <http://specialchildren.about.com/od/specialeducation/a/schoolprintouts.htm>

What parents would like special educators to know:

<http://specialchildren.about.com/od/specialeducation/p/wanttoknow.htm?nl=1>

What special educators would like parents to know:

http://specialed.about.com/od/idea/p/Parent_Support.htm

Want to learn how to improve YOUR relationship with your child's teacher? Register for our **Parent-Professional Collaboration** training available at our online training center (I would really like to recommend this training!): <http://www.parenttoparentnys.org/onlinetrainingcenter.htm>

Calendar of Upcoming Events:

- **The Path to Success: Meeting the Needs of Individuals with Neurological and Behavioral Disorders.** Presenters: Kathy Giordano of the Tourette Advocacy and Matt Giordano of Drum Echoes, Inc. Sponsored by The Advocacy Center. October 2 from 9:00 am-Noon at Girls Scouts of Genesee Valley, Inc., 1020 John St., West Henrietta. The presentation will feature how positive interventions can support individuals with disabilities and lead to success in a variety of

settings. There will also be a drum performance by Matt, after he shares his experiences of growing up with Tourette's Syndrome. Fee is \$40 or \$20 for parents and individuals with disabilities. For questions, please contact Anna Costalas at (800) 650-4967 or costalas@advocacycenter.com

- **My Body Politic: An Illustrated History.** A Multi-Media Performance featuring Simi Linton. October 2, 7:00 pm at Linehan Chapel, Golisano Academic Building at Nazareth College, 4245 East Avenue in Rochester. This event is free and open to the public. For questions please contact [Susan Taylorbrown@urmc.rochester.edu](mailto:Susan_Taylorbrown@urmc.rochester.edu) or call (585) 275-7006.
- **Disability Awareness.** October 6 from 6:30-8:00 pm. This workshop is designed to heighten awareness and acceptance of people with disabilities. To be held in Steuben County at North Cohocton United Methodist Church. Please call the church at (585) 534-5609 for more information.
- **On the Same Page: A Summit for Family Engagement in Education.** October 6 and 7 at the Desmond Hotel and Conference Center in Albany. Hosted by New York State Parental Information & Resource Centers (PIRC), EPIC—Every Person Influences Children Inc., New York State PTA. For additional information or questions, contact Shelley Richards at (716) 332-4140 or email summit@epicforchildren.org or go to the website: www.samepagesummit.org
- **Pink Wheels Work—Exploring Job Readiness for Young Women with Disabilities.** October 10 at the Syracuse Renaissance Hotel. Keynote speaker is Andrea Haenlin-Mott, ADA Coordinator for Facilities Services at Cornell University. This is a mentoring event that will allow young women aged 16 through 26 to learn from women with disabilities who have successfully entered the workforce. This event is free and includes lunch; but you must register by October 1st. Contact Deborah Oonk at (315) 410-3384 or go to: www.enablecny.org/uploaded/PWW%202008%20Registration%20Brochure%20revised.pdf
- **Family Fall Conference by Chemung ARC.** October 11 from 8:30 am-3:00 pm. For families of children with special needs. Keynote Speaker: Dr. Al Condeluci, CEO of UCP/CLASS of Pittsburgh presenting on cultural change and community inclusion. Breakout sessions will include presentations by Mary Jo Hebert and Sharon Marrella of **Parent to Parent NYS**, Dr. Caroline Magyar of University of Rochester and Rochester Regional Center for Autism Spectrum Disorders, and Dr. Breen a pediatrician and also a consultant for OMRDD. Held at Corning Community College's Academic & Workforce Development Center, 318 Madison Avenue in Elmira. Continental breakfast and lunch is included. Fee is \$10, refundable the day of the conference. (Scholarships are available.) Childcare is also available, featuring puppeteer program Kids on the Block, with pre-registration. Registration for this event is REQUIRED and space is limited. For more information please call Shelley at (607) 734-6151 x 112, email her at SAJ@ChemungARC.org or go to the brochure on the website at: <http://www.chemungarc.org/Fall%20Family%20Conference.pdf>
- **Advocacy Steps 101.** October 11 from 10:00-11:00 am. Sponsored by Heritage Christian Services and held at Pieters Family Life Center in Rochester. This workshop will outline the basic steps of effective advocacy. There is no fee, however registration is required. Please contact Julie Buick at (585) 487-3502.
- **Adolescence and Sexuality.** October 14 from 7:00-9:00 pm. Featured speaker: Dr. Lori-Jeanne Peloquin, Ph.D. Held at AMSA Conference Room, Al Sigl Center, 1000 Elmwood Ave., Rochester. To register, go to contact@unyfeat.org or call (585) 234-1220 by 10/13/08.
- **We Are Family—In Celebration of Grandparents and Relative Caregivers.** October 19 from 1:00-2:30 pm and sponsored by The Second Time Around Parents. Held at Cornell Cooperative

Extension of Ontario County, Lower Level Auditorium, 480 N. Main St., Canandaigua. This event is free by you must RSVP by October 15th by calling (585) 394-3977 ext. 425.

- **UNYFEAT First Annual Conference.** October 20-21 from 8:30 am-3:30 pm. Featuring Barry Prizant, PhD. CCC, SLP, discussing the SCERTS Method, "Social Communication, Emotional Regulation & Transactional Support." Held at the Burgundy Basin Inn in Rochester. For more information, call (585)234-1220 or email at Contact@UNYFEAT.org or visit the website at www.UNYFEAT.org
- **Augmentative Communication.** October 22 from 6:00-8:00 pm. Speaker: Elizabeth Begley, Clinical Assistant Professor, School of Speech, Language and Pathology/Audiology for Ithaca College. Held at Cayuga Medical Center, Howell Wing, Room D, 101 Dates Drive, Ithaca. Professor Begley will demonstrate the latest in equipment used to enhance communication in individuals with developmental disabilities. For more information, please call (607) 432-0001 or 800-305-8814.
- **Exploring Autism 2008: Emotional Self-Regulation in Children, Adolescents and Adults on the Autism Spectrum.** Sponsored by Regional Conference on Autism and Asperger's Syndrome. October 25 from 8:15 am-4:30 pm at the Holiday Inn Electronics Parkway, Liverpool. Seating is limited and the fee is \$70 for family and students and \$90 per professional if received before 9/15. (\$10 more each after) Information and brochure available at www.rcaas.org or by calling Mark Schneider, Ph.D. at (607) 434-1069.
- **Understanding and Supporting Students with Autism Spectrum Disorders.** October 28 from 8:30 am-3:30 pm. Held at The Holiday Inn, Ithaca Downtown, 222 South Cayuga St., Ithaca. Presented by Center for Autism and Related Disabilities (CARD). This FREE seminar is open to parents and professionals. One part will look at how the core and associated characteristics of autism spectrum disorders impact a student's learning and behavior. Another part will discuss the essential components of a functional assessment of behavior. Space is limited and pre-registration is REQUIRED. For more information, call (518) 442-2574 or (866) 442-2574 or by email at card@albany.edu Conference brochure available at: http://www.albany.edu/psy/autism/Ithaca_PDPS_Flyer.pdf and the registration flyer can be accessed at: http://www.albany.edu/psy/autism/PDPS_schedule.htm
- **S.E.A.D.S 2ND Annual Informational Services Fair.** October 29 from 6:00-8:00 pm. Held at EOP, 650 Baldwin St. Elmira from 6:00-8:00 pm. Come learn more about the recreational and support services in your community to help your child who as special needs and your family. Activities for children, door prizes, refreshments. Please contact Wendy Watkins at (607) 734-6174 or Joyce Simons at (607) 734-3640 or Muscles4kids@yahoo.com for more information.
- **Challenging Behaviors in Individuals with Developmental Disabilities.** October 30 from 8:00 am-3:45pm. Sponsored by University of Rochester and Golisano Children's Hospital. Held at Burgundy Basin Inn, 1361 Marsh Rd., Pittsford. Keynote address: Beyond "Spit that Out!—Evidence-Based Approaches to Serious Pica with Cathleen Piazza, Ph.D., Center for Autism Spectrum Disorders and Pediatric Feeding Disorders, Munroe-Meyer Institute. Featuring 4 breakout sessions with a variety of speakers and a Speaker panel discussion. Fee is \$45 for families and \$90 for professionals due 10/17. For questions, please call Lisa Skavienski at (585) 275-3744 or email her at lisa_skavienski@urmc.rochester.edu For the brochure, please go to: http://www.urmc.rochester.edu/pediatrics/divisions/developmental_disabilities/documents/KirchConference2008.pdf
- **Special Speaking Engagement: Temple Grandin, Ph.D.** October 30 from 7:30-9:00 pm. Co-sponsored by Dept. of English, College of Liberal Arts at RIT and UNYFEAT. The Harley School, 1981 Clover St., Rochester. (Free shuttle available at First Baptist Church of Rochester.) Free

and open to the public. R.S.V.P. by 10/23 by registering at www.unyfeat.org or by calling (585) 234-1220.

- **Self-Advocacy Association of NYS Statewide Conference—No Tricks, Just Treats: Our Lives, Our Decisions.** October 30-November 1. Held at Marriott Hotel, 189 Wolf Road, Albany. Thursday night will feature a film, *Body and Soul*, presented by Cathy Conour & Diana Braun. Friday will feature a costume dance with the band, *Flame*. Commissioner Diana Ritter will join in several events, including an interview with “celebrity” advocates. Commissioner Ritter will also conduct 2 forums to respond directly to questions. For more information, go to the conference brochure at: <http://www.sanys.org/ConfBrochure08ProofA.pdf>

ONLINE INFO~

Are you a member of our Office E-group? Do you currently receive our Links Digest and other informative emails? Have you checked out our online training center at our state website? If you said “no” to any of these questions, please contact our office to learn more and to register today!
www.parenttoparentnys.org or Sharon Marrella at p2pnys_southern_tier@verizon.net

Some Helpful Websites—

Angel Food Ministries—to help those in need (Enter your zip for locations--\$30 cash or \$28 in food stamps required to participate. There is a deadline to pre-order.): www.angelfoodministries.com

NYS Board of Elections Voter Education (accessible ballot marking devices information—select your county for information): <http://www.vote-ny.com/index.php>

Disabled Children’s Relief Fund (DCRF): www.dcrf.com

Checklist and suggestions for teachers and parents of children with sensory needs
www.childrensdisabilities.info/sensory_integration/sensorydysfunctionteachers.htm

October is Learning Disabilities Month: http://school.familyeducation.com/learning-disabilities/growth-and-development/37757.html?WT.mc_id=FE_Your-Child_12-18_2008 (An age-by-age guide)

Coats for people who utilize wheelchairs: www.cozycoats.com

Teens and Autism: http://autism.about.com/od/transitioncollegejobs/Teens_and_Autism.htm

Creating Positive Health and Fitness Opportunities for people of ALL abilities:

http://ebulletin.us/archive/2008/october/10_08_creating_pos_health_fit/10_08_creating_pos_health_fitnss_oppor.php

Learning Disabled Adults in the Workplace (some interesting info):

<http://learningdisabilities.about.com/od/careerissues/p/LDAdultsatwork.htm?nl=1>

The Basics of Special Education:

http://specialed.about.com/od/idea/Basics_Special_Education.htm

Special Education School Terms: <http://specialchildren.about.com/od/specialeducation/tp/Special-Education-School.htm>

Autism Message Board: <http://AutismInOurTownNY.proboards80.com>

Make a Halloween costume: <http://childparenting.about.com/cs/holidays/a/makecostume.htm?nl=1>



Do you have a website to share?

Fall into Support...volunteer to become a support parent!

If you want to turn over a new leaf this spring, become a support parent. Offer a little of your time, share your experience, and be an emotional support to another parent. It doesn't require much time—no tricks! Nothing can compare to the support one can receive from someone who "gets it." Volunteer today and you will be that special support to some other parent!

If you have a child with a disability, then you know how difficult a journey it can be at times. ***We all have a story to tell, something to share with someone else.*** Training is available from our office for individual or group trainings, or at your own pace online at our state website:

www.parenttoparentnys.org However, your experience is the greatest resource you possess. Being a support parent is voluntary and can be done through phone calls or email. Remember how you felt when your child was diagnosed? Please consider being a support to another family by volunteering today. The support you offer can make such a difference for another parent.

Upcoming Trainings/Presentations by The Advocacy Center of Rochester

ASK THE ADVOCATE—October 27 from 4:00-5:30 pm and **IEP: INDIVIDUALIZED EDUCATION PROGRAMS**—October 27 from 6:00-8:00. Held at The Advocacy Center, 590 South Ave. Rochester. These events are free, but pre-registration is required. Please contact Anna Costalas at (800) 650-4967 or Costalas@advocacycenter.com to register.

LAY ADVOCACY TRAINING—Will be offered in the spring at the Arc of Schuyler beginning in March; it is tentatively scheduled to be offered in Bath in the fall. More information to follow. Consider taking the opportunity to take one of these training sessions while they will be in our region!

LOCAL SUPPORT GROUPS—

S.E.A.D.S. (Support, Education and Accessing Disability Services)—EOP, Inc., Ernie Davis Family Center, 650 Baldwin Street, Elmira from 6:00-8:00 pm on the last Wednesday of each month.

Please join other parents and caregivers of children with disabilities. All are welcome no matter what the diagnosis is (and a diagnosis isn't necessary to attend). For more information, please contact Joyce at (607) 734-3640 or at Muscles4kids@yahoo.com. Check out their new web link at: <http://muscles4kids.wetpaint.com> (Please see the info about their upcoming Info Fair above.)

Chemung ARC's Down Syndrome Support Group—711 Sullivan Street in Elmira from 6:00-8:00 pm on the third Wednesday of every month.

Please join other parents and caregivers of children with Down Syndrome to get together and share things. Special speakers arranged on an as desired basis. For more information, please contact Chemung ARC at (607) 734-6151.

Celiac Sprue Association of Southern Tier Celiac Chapter No. 115 (Celiac Support Group)—Ye Olde Chapel Meeting Room of St. Joseph's Hospital, Elmira from 7:00-8:45 pm on the first Thursday of each month.

Please join other parents and caregivers, plus adults with Celiac Sprue, for information and support. For more information, please contact Janet LaRue at (607) 565-3477.

START (Southern Tier Autistic Resource Team)—Corning Public Library, 6:00-8:00 pm on the fourth Thursday of each month.

Please join other parents and caregivers of children with autism spectrum disorder to share information and support. The group welcomes new members. For more information, please contact Belinda at bvandright@yahoo.com

Traumatic Brain Injury Support Groups—In BATH—Kinship Family & Youth Services, 130 Rumsey Street, Bath, 6:00-7:30 pm on the third Monday of each month. In GENEVA—Presbyterian Church, 24 Park Place, 6:30-8:00 pm on the first Monday of each month.

Please join other parents and caregivers of children with TBI as well as people with TBI to share information and support. Both groups welcome new members; just R.S.V.P. For more information, please contact Sharon Johnson at (315) 538-8018 or email her at sjohnsonbia@rochester.rr.com

Sweet Kids (For Children with Diabetes)—Clute Educational Building, Arnot Ogden Medical Center, Roe Street, Elmira from 6:00-7:30 pm on the fourth Wednesday of each month.

Please join other parents and caregivers of children with diabetes. For more information, please contact 607-737-4499.

~Would you like to have your support group information listed here? Please contact the office to be included in the next newsletter. Thanks.

Advocacy Building Corner



The school year is underway and our kids have hopefully settled into the new school year. While we worry about pencils, notebooks, new sneakers and bus schedules this time of year, many of us don't focus much time on our child's IEP or 504 Plan. Unless you have had a meeting, a conference or had an issue come up, you might not have done more than file that plan away. However, NOW is a good time to refresh your memory about what is actually written in your child's IEP or 504 Plan. Does your child need homework modifications? Is your child receiving the accommodations he/she needs in the classroom? Who will contact you if there is a medical emergency for your child? Do you know ALL of the services and therapies your child is receiving this year? Does your child have special transportation accommodations or arrangements? All good questions—and good reasons not to let time slip by until the next meeting or teacher conference.

It is a good idea to review your child's IEP or 504 Plan to assure what you thought would be provided to your child is expressly stated on the document. Remember, this is a legal document; if it is on the IEP or 504 Plan, it must be done. Yet many parents don't actually take the time to review their child's IEP or 504 Plan when they first receive it. And if something is not expressly stated on the document, it may not necessarily be done. For example, if your child requires homework modification in math, make sure it is clearly stated on his IEP. If your child requires medication during the day, make sure the time, person who will administer the medicine and place (usually the nurse and her office) are specifically stated on her 504 Plan. If your child is allowed a CD player on the bus for sensory needs, make sure that is clearly stated under transportation needs and the bus driver is made aware of the accommodation.

The beginning of the school year is also a good time to make sure that the modifications and accommodations our children receive continue to be appropriate. Is time-and-a-half for test taking enough of an accommodation—or would your child benefit from having that changed to twice the allotted time for test taking? Does your child with diabetes have ample opportunities to maintain his/her blood sugar throughout the day? By approaching your child's academic team with these types of questions now, you might prevent some issues further into the year. Also, if appropriate, consider making your child aware of the modifications and accommodations in their plan. This can help a child begin to learn how to advocate for themselves. It doesn't have to be overly sophisticated in wording either. My son knows if he is having problems understanding a particular subject, he can go to a specific teacher for assistance. I don't need to give him more information than, "If you don't understand go ask Mrs. C for help." But, even that empowers him to speak-up (at least sometimes) when there is a substitute teacher who may not be aware of his needs. Giving him that information gives him the assistance he is eligible for, reduces anxiety, and is in compliance with his plan. (How do I know? I checked!)

So, dust off your child's IEP or 504 Plan and read it. Consider this your homework for your child. As if you needed more incentive...first report cards will be coming home in just a few weeks.

Would you like some more information? Check out the Education Resource Page at our state website: http://www.parenttoparentnys.org/Library/Education/education.html#Section_504_Accommodation_Plans and be sure to check out the **Section 504 links** and the **Special Education links** and resources listed near the bottom of the page.



Do you know how to knit or crochet? Or do you know someone who does? Consider donating your talent to help keep a Special Athlete Warm this winter. Coats and Clark is seeking donations of completed scarves to supply every athlete attending the 2009 Special Olympics World Winter Games in Idaho; 5,000 scarves will be needed. The only request is that you use a specific type of yarn in the Special Olympic colors. For more information and specifics, go to the website: <http://www.coatsandclark.com/Crafts/Crochet/Features/Special+Olympics.htm>

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**Cold and Flu season is coming!** Ah, yes...it's snuffle time once again. For many of us though, this isn't just an annoying time of year—it's a time we actually dread. When you have a child with special health concerns, the thought of a cold or flu virus taking up residence in your home is truly a frightening one. Since the birth of my younger son, our whole family has been required to receive a flu shot to prevent unnecessary risks to his health this time of year. It is actually a good idea to consult with your family physician to see if your family should be following the same practice if you have someone in your home with a compromised immune system or special health concern. Contact your local county health department as well to see if there are flu clinics in your area. **NOW** is the time to get your shot to be most effective. However, if your child has an allergy to eggs, the flu shot may **NOT** be right for him/her. *Again, please talk with your family physician first.* For more info on how to help prevent the spread of colds and flu in your house, check out the following website for a helpful checklist: <http://life.familyeducation.com/disease-prevention/illness/47943.html?detoured=1>

If your child does have special health concerns, do you have one of our **Health Care Notebooks**? If not, you can go to our state website to view it online at [www.parenttoparentnys.org/Family2Family/Record%20Keeping/Notebook/notebook.htm](http://www.parenttoparentnys.org/Family2Family/Record%20Keeping/Notebook/notebook.htm) They really do help keep track of all of that medical info we are supposed to be able to recall about our children!



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November 2nd—Daylight Savings time ends—Set your clocks back 1 hour before going to bed on Saturday the 1st.
November 4th—Election Day. Get out and vote!

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Have you seen the revised look of our state website? Check it out for yourself at [www.parenttoparentnys.org](http://www.parenttoparentnys.org) and browse through the different links.

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Please share this newsletter with other parents and agencies.  
Let people know about **Parent to Parent of NYS!** Thanks.

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