



The **STAR**

SOUTHERN TIER AREA RESOURCES

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

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

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Give the gift of learning—to you!

The hectic holiday season is here, the year is about to end; why not give yourself the gift of a training opportunity? You can even consider one of our online trainings if you can't attend a workshop in person. 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



“It’s the most wonderful time of the year”...*unless*...you consider the extra stress associated when combining holidays and children with special needs. The extra preparation, time, effort, planning and stress this time of year brings for parents and caregivers like us—above the usual holiday stress. And here’s the thing—it is almost like its own unique holiday tradition when you think about it. For a lot of us, this time of year brings the same challenges and extra planning that other families don’t understand or deal with in their homes. And to prove that point, part of this opening might remind the e-group faithful of last year’s newsletter opener. *That’s because for many of us, the holiday season doesn’t change that much from year to year.* We still have the same issues to contend with each holiday season.

Someone outside our situation can’t begin to understand the frustration when you have a child whose idea of the holidays doesn’t even remotely resemble that of a Norman Rockwell painting. Throw family into the mix and well, you can have a situation that screams “headache.” So, here we are with Thanksgiving right around the corner and extended family has begun the annual bargaining (read outrageous cash bribe in my older son’s case) to get their version of a “perfect holiday.” They might mean well; **but they just don’t get it.** Accept it. Except that many times we are doing battle with the “Martha” idea of the holiday. So what if Thanksgiving includes popcorn chicken and barbecue sauce instead of turkey and cranberry sauce—does that really matter? Shouldn’t we give thanks for being together rather than focusing on a preconceived notion?

The holidays can be extremely stressful for families who have special health care concerns and dietary restrictions. Children as well as adults look forward to special treats around the holiday season, home baked goodies they don’t have throughout the rest of the year, or maybe just an extra serving of mashed potatoes! For children with dietary restrictions, it is important to be sensitive to their needs.

Holiday parties in the classroom can be very difficult for children who are not able to participate. Be sure to have items available that will feel like a special treat for them whether it's a small token or prize. For family gatherings, keep in mind the special needs of others you may not see often and make sure you have things available for them. It can't hurt to call ahead and ask!

On the other hand, it may be the differences in routine and sensory issues that impact your child. Maybe your child with sensory needs simply can not stand all those light displays in the store—especially if they are *blinking*. Or, the sound of Christmas music this early in the season sets off your child with Asperger's Syndrome because it isn't logical. (They do have a point...) Or traveling with your child and their special medical equipment and prescriptions gives you such a chill that Jack Frost would be envious. How to survive the next couple of months? Consider some of these suggestions and remember that getting through the day is triumph enough sometimes. We also need to remember that we as parents must take care of ourselves too. So, indulge in a cup of hot cocoa and a *store bought* cut-out cookie while you visit these sites. If you have some suggestion that have worked for you, send them to me. If I receive enough that I think others would enjoy, I'll share them in an email. For more ideas, check out these websites:



Surviving the Holidays: <http://specialchildren.about.com/od/holidays/a/holidayhelp.htm>
<http://www.ncl.org/content/view/1114/>

Holidays & Autism: <http://autism.about.com/od/copingwithautism/f/holidayfaq.htm>
http://www.autismspeaks.org/community/ownwords/intheirownwords_thanksgiving_tips.php
Preemie in the hospital for holidays: http://www.suite101.com/article.cfm/premature_babies/30310
<http://www.helium.com/items/1038059-guide-to-holiday-decorating-with-a-special-needs-child>
How to have a happy holiday with your child: <http://www.idonline.org/article/11894>

Reducing Stress: <http://psychcentral.com/lib/2007/special-occasions-and-special-needs-kids/>
<http://www.specialneedsparentcoach.com/holidaytips/>
www.newsforparents.org/expert_ten_tips_reducing_holiday_stress.html (general info, but still good)
<http://specialchildren.about.com/od/needalaugh/ss/specialcarols.htm> (different parent humor)

Special Diets: Good overview on different special dietary needs:
<http://montgomeryadvertiser.com/article/20081118/LIFESTYLE/811180301>
www.gourmetspot.com/specialdietfeature.htm
www.diabetes.org/nutrition-and-recipes/holiday-meals.jsp
<http://tracker.diabetes.org/myfoodadvisor.html>
Healthier holiday recipes for all: <http://www.medicinenet.com/script/main/art.asp?articlekey=58593>

Diabetes Recipes: (lots of recipes on this site—some are for older taste buds)
<http://www.dlife.com/dLife/do/recipe/ProcessRecipeSearch?category=Holiday%20Recipes>
<http://www.diabetes.org/nutrition-and-recipes/holiday-meals.jsp>
<http://tracker.diabetes.org/myfoodadvisor.html>
<http://www.tasteofhome.com/Recipes/Special-Diets/Diabetic> (enter "holiday" in the search box)
http://www.diabetic-recipes.com/cat_holidays.htm

Gluten Free Recipes: <http://glutenfreemommy.com/recipes/>
<http://www.celiac.com/>
<http://www.csaceliacs.org/recipes.php>
<http://www.wholefoodsmarket.com/holidays/recipes/glutenfree-dairyfree.php#treats>

Sensory Needs: <http://www.sensory-processing-disorder.com/sensory-strategies-for-holidays.html>
<http://www.sensorysmarts.com/holidays.html>
www.fraser.org/tip_sheets/weighted_animal.pdf (Instruction sheet)
www.fraser.org/tip_sheets/weighted_blanket.pdf (Instruction sheet)
www.fraser.org/tip_sheets/travel_weighted_blanket.pdf (Instruction sheet)

Special Health Concerns & Holiday Travel: For children with Asthma and allergies:

<http://www.familytravelforum.com/articles/p/12130/article/10197>

http://specialneedsparenting.suite101.com/article.cfm/special_needs_for_holiday_travel

Airline travel & special needs: http://findarticles.com/p/articles/mi_go2827/is_ai_n28994259

Dealing with Family: <http://specialchildren.about.com/od/inthecommunity/a/holiday.htm>

www.associatedcontent.com/article/405962/how_to_visit_relatives_with_your_special.html (right side)

www.bellaonline.com/articles/art37114.asp (For Grandparents of Children with Special Needs)

Holiday Traditions: http://www.ehow.com/how_2148394_holiday-traditions-children.html

http://kids-holiday-activities.suite101.com/article.cfm/how_to_celebrate_christmas_with_your_kids

<http://betterkidcare.psu.edu/ParentsCount/ParentsCount0501.pdf> (Stress tips on page 2 as well.)

Less Materialistic Holiday: http://kidshealth.org/parent/positive/talk/holidays_materialistic.html

Out in the Community <http://holidays.about.com/od/relationshipsfamily/a/worship.htm> (Church and the child with special needs)

<http://ici.umn.edu/products/impact/143/over09.html> (Jewish participation for child with special needs; focuses mostly on Bar Mitzvah, but still has good general ideas for participation)

Simple Crafts: <http://www.papersnowflakes.com/>

<http://holidays.kaboose.com/> (Just enter what holiday you are looking for in search.)

<http://familyfun.go.com/arts-and-crafts/season/specialfeature/christmas-crafts-ms/>

http://parentingteens.about.com/od/craftsxmas/Free_Christmas_Craft_Projects_for_Teens.htm

Keep kids learning over break: <http://specialchildren.about.com/od/learningissues/tp/learnvacation.htm>

<http://specialchildren.about.com/od/learningissues/a/games.htm>

Special Toys (*NONE of these websites are to be considered endorsed by Parent to Parent of NYS. This are just some examples of options that are available to parents.*)

<http://www.specialneedstoys.com/usa/>

<http://www.toysrus.com/shop/index.jsp?categoryId=3261680>

If you do not have internet access at home, you can try these websites at your local library or contact the office for print out copies of the topics that pertain to your situation. Enjoy your holidays—however they occur in your house. May you all have a relatively peaceful and safe holiday season.



Calendar of Upcoming Events:

- **Understanding and Supporting Students with Autism Spectrum Disorders.** Presented by Center for Autism and Related Disabilities (CARD), SUNY Albany. On December 3 from 8:30-3:30 at The RIT Inn and Conference Center, 5257 West Henrietta Road, West Henrietta. Registration is REQUIRED for this free event; space is limited. For more information call (866) 442-2574 or go to http://www.albany.edu/psy/autism/Rochester_PDPS_Flyer.pdf for the flyer or go to http://www.albany.edu/psy/autism/PDPS_schedule.htm and scroll down for the registration form.
- **Sibshops**—Winter 2008/Spring 2009 Series. Co-sponsored by Continuing Developmental Services and Finger Lakes DDSO Family Support Services. Sibshops will be held from 10:00-12:00 at CDS Life Transition Center, 860 Hard Road, Webster. Recreation opportunities are also available for children with disabilities so that parents and siblings can attend their groups. Some

age restrictions apply; individuals MUST have a sibling who is OMRDD eligible. Saturday dates will be held on the following dates: 12/13/08, 1/10/09, 1/24/09, 2/14/09, 2/28/09, 3/14/09, 3/28/09, 4/11/09, 4/25/09, 5/9/09, 5/16/09, 6/6/09, 6/20/09. For more information, please call Shannon Doherty, Parent Support Coordinator at (585) 347-1059 or email her at sdoherty@cdsunistel.org

- **Save the Dates—2009 Autism Spectrum Disorder Regional Conference Series.** April 22nd in Canandaigua, April 29th in Elmira, May 6th in Auburn. 8:30-12:00 for conference topics determined by regional survey and community resource fair in the afternoon. For more information call (888) 806-9526.

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—

November is Prematurity Awareness month—sign the March of Dimes petition:

<http://www.marchofdimes.com/padpetition/index.aspx?a=1&z=1&c=1&l=en>

November is Diabetes Awareness month—learn more: http://www.diabetes.org/communityprograms-and-localevents/americanidiabetesmonth.jsp?WTLPromo=HOME_flash_102908adm



December is Seasonal Depression Awareness month—learn more about SAD:

<http://depression.about.com/b/2007/12/01/december-is-seasonal-depression-awareness-month.htm>

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

Jobs, Careers, and Callings: Deaf and Hard of Hearing People at Work website: <http://deafhcareer.com/>

International Day of Persons with Disabilities - 3 December 2008 declared by UN Enable: <http://www.un.org/disabilities/>

Do you have a website to share?

Give a gift from the this holiday season—Become a Support Parent!

If you would like to give a “gift” that will truly make a difference for someone, 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—which is a good thing given the holiday stress! Nothing can compare to the support one can receive from someone who “gets it.” Volunteer today—earn points with Santa!

If you have a child with a disability, then you know how difficult a journey that 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, doesn’t require much time 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 becoming a support parent. The support you offer can make such a difference for another parent.

Upcoming Trainings/Presentations by The Advocacy Center of Rochester

LAY ADVOCACY TRAINING—This 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 note that the December meeting will be on the 17th due to the holidays. It will be a holiday party open to all—past members as well as new. Please R.S.V.P. in advance if attending. For more details, contact Joyce (info 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. Please visit their website: <http://home.stny.rr.com/zpage2b/START4.html/> For more information, please contact Belinda at bvandright@yahoo.com **Please note that the December meeting will be on the 11th due to the holidays. It will be a holiday party with crafts for the kids. Please R.S.V.P. in advance if attending. For more details, please go to the website listed above.*

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.



Extended School Year (ESY)—Now is a good time to be thinking ahead! What? There is snow on the ground, how can I think about summer? (Except for wishful thinking?) The reality is that this is a perfect time to consider how your child adapts to routine change during school breaks. Does it take your child a period of time to get back in to the school routine after a break? Does your child have problems with the unstructured time inherit in long breaks from the classroom? Part of the rationale for collecting information about school breaks now is because regression is ONE PART of determining eligibility for ESY (particular disability and needs are also other items to be considered). Please note that ESY and Summer School or Summer Enrichment are **not** the same things. A CSE meeting must be held to determine eligibility for ESY and the goals for that 4-6 week program. Summer school or summer enrichment does not necessarily require an IEP to participate. You can begin collecting information now if you think your child requires ESY services—notes from his/her teacher, communication book, behavioral referrals are some examples of things to collect. Take a look at some of the websites below to learn more about ESY now.

- <http://www.vesid.nysed.gov/specialed/applications/esy/ga2008.htm>
- <http://specialed.about.com/od/idea/a/ESY.htm>
- <http://www.greatschools.net/cqi-bin/showarticle/1210>

Remember, ESY is not a given. It must be decided upon in a CSE meeting and clearly stated on a child’s IEP or addendum to the IEP.



December 1-5 is Inclusive Schools Week. This year is the 8th annual observance. Promote inclusive practices all year-long! To learn more go to <http://www.inclusiveschools.org>

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**New York Chiropractic College in Seneca Falls to host 2009 / 2010 State Fall Games!** The Fall games will be in OUR region beginning next year! You can read the whole article at: [http://nyso.org/newsdetails.php?news\\_id=301](http://nyso.org/newsdetails.php?news_id=301) You may also want to navigate the site to volunteer, donate, or for an athlete registration form.

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Holiday Mail for Heroes

This year, consider including an extra holiday card for our men and women in uniform. From the American Red Cross website (<http://www.redcross.org/email/saf/>): “Our goal is to collect and distribute one million holiday cards to spread holiday cheer and facilitate thanks to these brave individuals and families.” Please send cards to this address:



Holiday Mail for Heroes
PO Box 5456

Capitol Heights, MD 20791-5456 There are VERY specific guidelines you must follow to participate. Be sure to go to the website listed above for details. All cards must be postmarked by **12/10/08** to be sent. Any received after that will be returned.

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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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