



The **STAR**
SOUTHERN TIER
AREA RESOURCES



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

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Aahhh, summer!

With the end of the school year, CSE meetings completed, report cards received, transition plans for next school year completed and questions about how to keep kids and young adults occupied for the summer, summer has its own mix of stress and relaxation. Of course there are still baseball games, cook-outs, planning for rainy days and soaking up the sun for the winter months ahead. Before the long sunny days slip by, take a moment to expand your knowledge. 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 seems unfair that Mother's Day and Father's Day come around once a year.

Especially when it seems we spend a great deal of time focused on our kids. My oldest, when he was much younger, asked, "When is it Kid's Day?" I looked at him and honestly replied, "Everyday!" So, here is one more chance to honor the mothers and fathers (grandparents and caregivers too) for all we do. Be sure to work some "ME" time into your summer to help recharge **your** batteries.

Ode to Parents like Us

Last time I checked, there wasn't a section in Hallmark for parents of children with special needs. There really should be. However, since there isn't...here's my humble attempt to address the need...

There really should be KUDOS...

For the parent who cheers when their child "hits" a baseball like it's "The Babe" reincarnated, regardless of the outcome of the swing.

For the parent who tries to make a hospital room seem less severe by bringing blankies and lovies from home.

For the parent who keeps trying to learn a new language—whether it be Special Ed, medical jargon, emerging Sign Language, transition buzzwords or insurance bureaucracy. And for the parent who keeps up on their fluency in these areas and then attempts to translate teen slang into simpler, albeit edited, words for their child to comprehend.

For the parent who wakes up in the middle of the night and goes to check that the packed lunch has the right treat, juice, sandwich or whatever else is important because their dear spouse made it for their child. However, you just want “to check” because of sensory needs, anxiety, or to make sure that it doesn’t exceed the carb count for your child’s special diet.

For the parent who realizes tying your shoes is an extraordinary accomplishment of motor skills, dexterity, memory and engineering. And for the parent who realizes that Velcro is a God-send.

For the parent who cries when their child is caught in an age-appropriate lie—not because they lied—but because it was considered “typical.”

For the parent who proudly hangs any piece of artwork created by their child since they know the effort it took for their “Picasso” to create such a masterpiece.

For the parent who wants to storm in when their child is taunted by peers, for the parent who allows their child the chance to face such taunts, for the parent who reminds the school bullying hurts everyone, for the parent who gives their child a means to advocate for themselves when this happens. And for the parent who cries in their heart when any of these occur.

For the parent who doesn’t lie when the medical procedure is going to hurt—but continues to hold their child’s hand through the screams and the tears.

For the parent who is exhausted at the end of the day just because they made it through another one.

For the parent who has learned to turn everyday activities into therapy session out of necessity.

For the parent who “heartily encourages” (not forces) some kind of sibling bonding since they know that will be the longest relationship their child will ever have during their life.

For the parent who has learned to spot an allergen, food or otherwise, from across a room without any hints and without formal CSI training.

For the parent who perseveres when everyone else doubts their tenacity. And for the parent who continues despite their own fears and doubts.

For the parent who feels more like a short order cook than a gourmet chef in the kitchen but realizes that some semblance of harmony is more important than none.

For the parent who knows the CSE Chairperson, therapists and medical supply company’s representative by first name.

For parents like us...who KNOW there is no manual for special needs...but “write” one everyday we keep going through this unexpected journey know as life...may we find the strength and perseverance to keep trying. Never underestimate you experience or your worth.

~Sharon Marrella



Calendar of Upcoming Events:

- **Parent to Parent of NYS will have a booth promoting Special Needs Awareness at the Indy Car Series at Watkins Glen International.** July 3 from 10-5 and July 4 from 10-3. Visit our booth and share the news with others.
- **Vicarious Trauma--The cost of Caring.** Presented by JoAnn Jankoski, EdD, MSW, MS and sponsored by The Advocacy Center. 8/4/10 from 8:30 am - 12:00 noon at St. Anne's church, 1600 Mt. Hope Ave. in Rochester. The cost is \$35 or \$30 @ for groups of 5 or more. Flyer and registration form at: <http://www.advocacycenter.com/pdf/VT10.pdf> . Questions, contact Anna Costalas at 800-650-4967 or costalas@advocacycenter.com
- **2010 Summer Inclusion Institute.** August 1-3 at Minnowbrook Conference Center in Blue Mountain Lake, NY. Co-sponsored by Parent to Parent of NYS, The Adirondack Arc and AAIDD. How do we move inclusion from a good idea to everyday life? How do we build community partnerships that really work? For more information, contact Les Parker at (518) 891-6565 ext. 114 or by email at inclusion@adirondackarc.org To view the flyer:

<http://www.parenttoparentnys.org/PDFs/Dated/2010%20Summer%20Inclusion%20Institute%20Req%20Form.pdf>

- **2010 Rene Jones Memorial Buddy Walk.** August 14 with registration at 9-9:45 am and Opening Ceremonies at 10:00 am. Location is Eldridge Park, E Thurston St. & Eldridge Park Rd., Elmira. Sponsored by Down Syndrome Information Network of the Twin Tiers. To register go to www.buddywalk.kintera.org/dsintt or contact Christine Heckle at (607) 738-9156 or dsintt@gmail.com

Our Office E-group has changed! Are you a member of our new **Yahoo E-group**? Would you like to receive our *Links Digest* and other informative emails? Were you a past member and now realize that your inbox is no longer receiving emails from Parent to Parent of NYS? If you said “yes” to any of these questions, please contact our office to learn more and to register today! You can join by going to <http://groups.yahoo.com/group/P2PNYS4STE> and select “join this group.” You can also request to join through our statewide website www.parenttoparentnys.org and selecting “Southern Tier” or by Sharon Marrella at p2pnys_southern_tier@verizon.net
Join the new Yahoo Group!!

Some Helpful Websites—

Guidebook for young adults with disabilities to advocate for their own health care. It includes checklists and activities. (from New Jersey)

<http://rwjms.umdnj.edu/boggscenter/products/BeingaHealthyAdultHowtoAdvocateforYourHealthandHealthCare.html>

June is Home Safety Month. Check out the article on summer safety.

<http://www.homesafetycouncil.org/index.asp>

Summer Survival Kit from about.com: <http://specialchildren.about.com/od/holidays/p/summersurvival.htm>

Tips for a Sensory Successful Summer:

<http://www.devdelay.org/newsletter/articles/pdf/371-sensory-successful-summer.pdf>

Summer Craft Ideas <http://crafts.kaboose.com/holidays/seasons/summer/> and

<http://crafts.kaboose.com/crafts-for-teens.html>

Do you have a website to share?

Your summer project...making a difference this summer by becoming a Support Parent!



If you would like to do something 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 and is really worthwhile! Nothing can compare to the support one can receive from someone who “gets it.” Volunteer today!

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

Creating Your Advocacy Notebook. September 20 from 6:00-8:00 pm in Dundee. This workshop provides parents with the skills, knowledge, and resources to maintain documentation and records that they will need to be effective advocates for their children. Participants will learn how to plan and prepare for school meetings, CPSE meetings, organize records and communicate with staff effectively. This workshop is free, but you must pre-register to attend by 9/17/10. To register, contact Anna Costalas at 585-546-1700 or 800-650-4967 ext. 265. To see the flier go to:

http://www.advocacycenter.com/pdf/092010_Advocacy_Notebook_Dundee.pdf

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>

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—days and dates TBD as of right now.

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/>

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.

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.



Individualized Health Plan (IHP)—should your child have one? When it comes to advocating for children, parents learn about many forms and different terminology. However, many people—parents and professionals alike—are not familiar with IHP. (Also called and Individualized Health Care Plan or Emergency Care Plan) An Individualized Health Plan is just what it sounds like except it can be attached to an IEP or 504 Plan to provide more specific information for a child with a special health care need. Not every one has one or necessarily needs one. If your child has a special health care need that requires medical intervention, skilled nursing services, may cause prolonged absences or has specific recommendations from a specialist for example, an IHP might be a good idea. Students with chronic asthma, diabetes, food allergies, etc. should consider one. While New York State does not have a standard IHP form, many schools do have their own IHP. (Check with your child’s school to see if yours does.) This is more than just listing your child’s special health care needs or medical alerts on an IEP or 504. This document should contain an actual plan to meet the needs of a child in a variety of settings: such as a school emergency, when the school nurse is not available (i.e. who will be the **trained** back-up to meet your child’s needs), when there is a substitute teacher, protocol for field trips, special alerts during transportation and for any other relevant times during an academic day. Working with your child’s doctor and/or specialist is a must to complete this document since he/she is familiar with the unique needs of your child. Working with your educational team (CSE/504 Committee) and the **school nurse** is essential to discuss and consider how the doctor’s recommendations will impact the academic day. The IHP should not be viewed as one more meeting to sit through but as a competent way to establish a plan to meet the needs of a child who relies on the professionals around him/her while in school. Having such a plan in place is one more way to advocate and keep our children safe and academically engaged. See the following links for more information or call the office if you have questions.

A good explanation for parents and professionals:

http://www.spannj.org/Family2Family/individual_health_plan.htm

Some sample IHP to consider: http://www.pacer.org/health/ind_health_plan.pdf

http://www.schools.nsw.edu.au/media/downloads/schoolsweb/student-support/studenthealth/individualstud/ind_health_plan.pdf

New York Statewide School Health Services Center—sample pages from the School Nurses Tool Kit:

http://www.schoolhealthservices.org/tool_kit.cfm?subpage=97

The following offer diagnosis-specific plans as examples that might be useful even though they would obviously need to be modified to fit other diagnoses or conditions. These plans actually offer more planning for a child’s day at school.

<http://www.mitoaction.org/files/Sample%20of%20Individual%20Health%20Care%20Plan.pdf>

<http://fite.peds.ufl.edu/resources/downloads/Health%20Care%20Plan.pdf>

If you would like more assistance or information, please contact the office.

When is the last time you visited our state website at www.parenttoparentnys.org –has it been awhile? Visit today and download this item we hope you will help us distribute:

[Respectful Language Bookmark](#) to download and share.

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Let people know about **Parent to Parent of NYS!** Thanks.