



The **STAR**

SOUTHERN TIER AREA RESOURCES

Newsletter for the Southern Tier Region of *Parent to Parent of NYS*
Serving Chemung, Schuyler, Seneca and Steuben Counties

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*Connecting and Supporting
Families of Individual with
Special Needs*

www.parenttoparentnys.org

Some Helpful Websites—

For an insightful look at Ability Awareness: www.imtyler.org
For a way to update family and friends on your child's upcoming surgeries, condition, etc.:
www.caringbridges.com
To find unique items for sale regarding the Special Needs Community:
www.cafepress.com
Disability News Radio:
www.disabilitynewsradio.com

Do you have a website to share?

Spring has sprung and summer is just around the corner...

For Mothers, Happy Mothers Day

A mother is the truest friend we have, when trials, heavy and sudden, fall upon us when adversity takes the place of prosperity when friends who rejoice with us in our sunshine, desert us when troubles thicken around us, still will she cling to us, and endeavor by her kind precepts and counsels to dissipate the clouds of darkness, and cause peace to return to our hearts.--Washington Irving

For Fathers, Happy Fathers Day

He opened the jar of pickles when no one else could. He was the only one in the house who wasn't afraid to into the basement by himself. He cut himself shaving, but no one kissed it or got excited about it. It was understood when it rained, he got the car and brought it around to the door. When anyone was sick, he went out to get the prescription filled. He took lots of pictures ... but he was never in them.-- Erma Bombeck (*Family--the Ties that Bind ... And Gag*)

With the end of the school year quickly approaching, why not check out upcoming workshops or try one of our **online trainings**?

<http://www.parenttoparentnys.org/onlinetrainingcenter.htm>

Do you know of an event or offer local information that might benefit other parents? Please email or call this office and we will help promote it.

Medicaid Service Coordination for Families—Getting the Most from Your Child's Program—Video Conference—May 1, 10:00 am-12:00 noon, FLDDSO, 620 Westfall Rd., Rochester

Presented by Parent to Parent of NYS. This video conference will cover the features and benefits for MSC, the rights and responsibilities of family members receiving MSC and what is an Individualized Service Plan (ISP). To register, go to www.omr.state.ne.us and select "Information for Providers" on the left menu. Scroll down and choose "Online Registration Form." For more information about this upcoming training, please contact Mary Jo Hebert at 800-305-8817.

Strategies for ADD/ADHD—Stress Management—May 3, 7:00 pm, Thomas High School Library, Webster

Presented by Webster Parent to Parent/SEPTA (*not affiliated with Parent to Parent of NYS*). For more information, contact brown@advocacycenter.com or call 800-650-4967 ext. 267.

Chenango Autism Conference—“Supporting Children with Autism Spectrum Disorders”—May 4, 8:15 am-4:00pm, Ballroom at Howard Johnson Hotel, Norwich.

Free for parents and individuals with autism, %75 for professionals. Sponsored by OMRDD, DCMO BOCES, The Family Resource Network and DDPC. For more information, please call 800-305-8814.

Living Life to the Fullest: Optimizing Health & Well-being for Persons with Physical Disabilities—Cerebral Palsy of Rochester, 3399 Winton Road South, Rochester. Each session is from 5:45-8:00 pm.

- ***Spasticity Management: Medical and Therapeutic Interventions—May 7***, Presented by Doug Fetkenhour, MD., Lorna Patanella, PNP, Karen Terp, PT, Ruth Fried, OT
- ***Psychosocial Aspects of Living with a Disability—June 4***, Presented by Laura Selke, Ph.D. and Connie Mastowski, LCSW-R.

Series sponsored by CP Rochester and Kirch Developmental Services Center. Fee is \$15 per session. For more information, please contact Nancy Straub at (585) 334-6000 ext. 252 or email n_straub@cprochester.org

2007 Reach for the Stars Conference—May 14, 8:00 am-3:00 pm, Doubletree Hotel (formerly Wyndham), Syracuse

Sponsored by Exceptional Family Resources, Syracuse. For more information, call (315) 478-1462 or go to www.contactefr.org and follow the link for “Upcoming Events.”

Presentations for Families and Friends of Children with Autism Spectrum Disorder, Strong National Museum of Play, 1 Manhattan Square Park, Rochester. Each session is 7:00-9:00 pm.

- ***Challenging Behaviors—May 16***, Presented by Christine Peterson, Ph.D. and Center for Autism and Related Disorders
- ***Enhancing Growth Through Play (All Ages)—June 20***, Presented by Lori Jeanne Peloquin, Ph.D.

Series sponsored by Monroe County Special Children’s Services & Service Providers. For more information, please call Dianne Weider at (585) 753-5250 or Jeanne Sloan at (585) 753-5205.

Auto Crafting Open House—May 18-20, 170 Jefferson Road, Rochester

Product displays, questions and answers, demonstrations regarding vehicle adaptations and modifications to promote accessibility. This is not a sales event. Refreshments will be served. For more information, or to R.S.V.P. to this event, please call (866) 889-1867 or hcurts@autocrafting.com

Spring Into Action: It’s as Easy as A, B, C—May 19, 8:00 am-3:00 pm, Pathways, Inc., 33 Denison Parkway West, Corning

Sponsored by Finger Lakes DDSO Consumer Council Region II, The Advocacy Center, New York State Disabilities Advocacy Association and Network, and Pathways, Inc. A free conference for parents and family members of children with developmental disabilities. Continental breakfast and lunch included. This is for parents and other family members of children with a documented developmental disability; a copy of your HCBS Waiver, Notice of Decision or OMRDD Eligibility Determination is required to register. For more information or if you have questions, please contact Pam Merkle at (800) 650-4967 ext. 237.

D-D Day—Nineteenth Annual Developmental Disability Awareness Day—May 24, 8:00 am-3:30 pm, Buffalo Convention Center, Buffalo

\$10 for workshops/fair only, \$30 Workshop/lunch. Registration deadline is May 9th. Walk-ins will be accepted, but lunch can not be guaranteed. Please call (716) 805-1555 for more information. Registration form may be obtained by contacting Karen Gustina at kgustina@sasinc.org.

You’re Going to Love this Kid: Educating Students with Autism Spectrum Disorders in Inclusive Schools—May 31, 8:00-3:30, Burgundy Basin Inn, 1361 Marsh Road, Pittsford

Featured speaker: Paula Kluth. Fee is \$65 (by May 4) for conference and it includes buffet lunch. If you didn’t receive the flyer from me previously, please contact me. (I have the flyer but no direct website link to send.)

The Impact of Employment of Disability Benefits and Medicaid Conference—May 31, 8:15 am-4:30 pm, St. John Fisher College, Golisano Gateway Middle Level, 3690 East Avenue, Rochester

Sponsored by Neighborhood Legal Services and the Empire Justice Center. Focusing on Employment and Persons with Disabilities: The Impact of Employment on Disability benefits and Medicaid and how to promote career development for youth and adults with disabilities. Registration fee is \$65 before 5/18 and \$95 after; this includes morning refreshments and all handouts (including the Benefits Management Manual). For more information contact Rachel Lauria and (716) 847-0650 ext. 271 or go to www.nls.org

Building on Our Past: Preparing for the Future—Brain Injury Association of New York State, 25th Annual Conference—June 7-8, Albany Marriott Hotel, Albany

Keynote speakers: Lee and Bob Woodruff (ABC News Anchor). A two-day conference including meals and workshops ranging from \$100 to \$350 depending on days attending, whether consumer or professional, and what days attending. Hotel fees are extra. For more information call (800) 228-8201 or go to www.bianys.org/events.html

Planning Today for Tomorrow—A Statewide Symposium, June 21, 8:00 am-4:30 pm, Empire State Plaza Convention Center, Albany

A presentation for long term care. For more information, please contact CDHS Registration Services at (716) 876-7600.

Upcoming Walks—

- ✓ **MARCH OF DIMES WALK AMERICA (For Healthy Babies/Prevent Prematurity)**—Saturday, May 5, Elmira area—Thorne Street Park (East of Horseheads High School football field), Horseheads and Tri-Lakes area—Seneca Lake State Park, Shelter #1, Geneva. For more information go to www.walkamerica.org
- ✓ **MS WALK (For Multiple Sclerosis)**—Sunday May 6, Corning/Elmira/Bath area—Painted Post East High School. For more information, go to www.msupstate.org

Do you receive our LINKS DIGEST? Our Links Digest is a compilation of current website links to help individuals gain further knowledge and skills related to advocating for a person with special health care needs. The topics include: *Advocacy 101, Financial issues, 504 Accommodation Plans, Record Keeping, Parent-Professional Collaboration, Who Help with What?, Parent-to-parent support skills building, Understanding Medicaid funded Waiver Services, Legal information, and Other health care links.* Please contact the office to join our e-group and receive the Links Digest via email. Most recent digests are available on the homepage of our website: www.parenttoparentnys.org

Upcoming Trainings/Presentations by The Advocacy Center of Rochester

The Advocacy Center's Second Annual Jazz Concert and Art Auction—May 12 (note the change in date), Memorial Art Gallery, Rochester—From 6:00-10:00 pm. Featuring Jimmie Highsmith, Jr., & Tyler Owens. Tickets \$35 in advance, \$40 at the door. Call (800) 650-4967 for more information or to purchase tickets.

SPECIAL EDUCATION WORKSHOPS—Offered at The Advocacy Center in Rochester. Choose either 10:00-12 noon or 6:00-8:00 pm. Call 800-650-4967 to register or for more information.

- **Transition**—May 8th
- **Due Process/Procedural Safeguards**—June 12th

FREE ADVOCACY WORKSHOPS—For parents of children with disabilities. Offered at various locations around the area. Please call 800-650-4967 for more information on locations and to register (**required**).

- **Overview of Positive Behavioral Interventions and FBA's**—May 16th, Geneva Free Library, 244 Main Street, Geneva, 6:00-8:00 pm.
- **CSE Overview and Ask an Advocate Q & A Session**—May 22nd, Rural Urban Center, 208 Broadway, Montour Falls, 5:45-8:00 pm.

SERVICE COORDINATORS TRAINING—Offered at The Advocacy Center in Rochester. From 9:00-12:00 noon for a fee of \$35.

- **Understanding Medical Issues and How to Help Organize Parents**—May 2nd
- **Understanding Neurological Behavioral Disorders**—June 6th

Parent Training & Information Center Special Education Monthly Topics

FET TRAINING—Held at The Advocacy Center in Rochester, 10:00-12 noon. Pre registration is required. For families of children who are on Medicaid Waiver who need FET credit to maintain eligibility.

- **Creating Your Advocacy Notebook**—May 17th
- **Understanding Medicaid, MSC, and Waiver Services**—June 21st

Call 800-650-4967 to register or for more information. Check out more information online at The Advocacy Center's website: www.advocacycenter.com

INFO ON 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



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.

Families & Friends of Those with Autism Spectrum Disorder—Southeast Steuben County Library, Corning

Please join other parents and caregivers of children with Autism Spectrum Disorder. For more information, please contact Patty at (607) 562-2263.

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

Would you like a copy of our **Guide to Understanding Supports and Services—Administered by NYS OMRDD?** This compilation is available by contacting the office or online at our state website—www.parenttoparentnys.org—by clicking on Health Care Information. This guide is very useful in understanding about eligibility, wide range of supports and services available and more. Please be sure to check this out for you and your family.

Advocating Through Letter Writing is a booklet that offers information and tips for parents. It is available from our office or from our state website—www.parenttoparentnys.org. This booklet will help you learn to become more effective in your letter writing. Please be sure to check this out for yourself and your family.

Visit our **ONLINE TRAINING CENTER**—www.parenttoparentnys.org to increase your knowledge in a variety of health care topic areas. All trainings are free of charge and can be done at your own pace and a time that is best for you. Be sure to check out the online trainings available: **Support Parent, Advocacy Skills & Techniques (for the Health Care system), Health Care Financial Resources, 504 Accommodation Plans, Community & State Health Care Resources, Health Care Record Keeping, Home Medical Care, Parent-Professional Collaboration and Health Care Legal Rights.** We also offer **Health Care Resource Parent and Community Leader** trainings. (These trainings have additional requirements specified on the website.) We continue to offer information to build your skills as a parent on our website. Please be sure to visit today.

Does your child have a special health care need or medical condition? Would you like to learn more about keeping track of all of their medical information and become a better record keeper? Now available through our office is the **Health Care Notebook and the Health Care Recordkeeping Training** that goes along with the notebook. It is a fantastic way to keep track of a variety of important medical information with highly useful forms that are easy to understand. It can be a vital tool in maintaining your child's health care information.

Please call the office to learn more if you are interested.

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

Happy Mother's Day and Happy Father's Day to all the parents, step-parents, caregivers and special people who take care and love the children—both young and older—in the Southern Tier Area.



One more time... I have been asked a few times where the name for this newsletter came from and to repeat the story that inspired the name. Since the number of the office E-group has grown considerably since the first edition in January of 2006, I thought I would include the “Starfish” story one more time. I think it is very apropos as we draw near to Mother’s Day, Father’s Day and the end of the traditional school year (even though some of us have children who continue on), and the beginning of summer. Remember, it is making a difference—*one at a time*. Enjoy and please encourage others to join our e-group.

“The Starfish Story,” adapted from *The Star Thrower* by Loren Eisely.

Once upon a time, there was a wise man who used to go to the ocean to do his writing. He had a habit of walking on the beach before he began his work. One day, as he was walking along the shore, he looked down the beach and saw a human figure moving like a dancer. He smiled to himself at the thought of someone who would dance to the day, and so, he walked faster to catch up.

As he got closer, he noticed that the figure was that of a young man, and that what he was doing was not dancing at all. The young man was reaching down to the shore, picking up small objects, and throwing them into the ocean. He came closer still and called out “Good morning! May I ask what it is that you are doing?”

*The young man paused, looked up, and replied “Throwing starfish into the ocean.”
“I must ask, then, why are you throwing starfish into the ocean?” asked the somewhat startled wise man.
To this, the young man replied, “The sun is up and the tide is going out. If I don’t throw them in, they’ll die.”*

Upon hearing this, the wise man commented, “But, young man, do you not realize that there are miles and miles of beach and there are starfish all along every mile? You can’t possibly make a difference!” At this, the young man bent down, picked up yet another starfish, and threw it into the ocean. As it met the water, he said, “It made a difference for that one.”



**Do you have a suggestion for an inspirational piece or story to share?
Please let me know and it might be included in a future edition of The STAR!**