



PA-TSA NEWS

PA TOURETTE SYNDROME ASSOCIATION, INC.

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Mission Statement

The Pennsylvania Tourette Syndrome Association is a nonprofit organization whose mission is to identify, support the needs of and advocate for individuals with Tourette Syndrome in Pennsylvania. To promote awareness of Tourette Syndrome through informational outreach and educational presentations.

Administrative Report

We are in the midst of the season of giving. In reflecting on this past year I am overwhelmed by the support we receive from all of you. As we, adults, continue to raise awareness about TS, an unsuspected group has surfaced and taken the lead in this role. I want to highlight this specific group of individuals that have really stepped up to the plate, **Our Children**. We have an increasing number of children coming forward to educate others about TS and raise funds for our organization. I wanted to take this time to recognize their efforts. These are some examples of the efforts that have been made this past year across the state.

Trinity High School Student Council hosted a Powder Puff Football Charity event.

Kayla Sloan appeared on FOX 43 news to promote TS awareness and her ongoing fundraiser, "Pennies for Kayla" to benefit PA-TSA. Kayla and her family also organized a night at a local restaurant where a percentage of the proceeds from that evening were donated to PA-TSA.

Lydia and Trent James held a bake sale at a local beauty salon where they raised money and awareness about TS.

Danny Fishbein made PA-TSA the beneficiary of his *Mitzvah Project*. Danny combined his love of sports with a cause close to his heart. Danny endeavored to run 100 miles to raise \$1,800 for PA-TSA.

Brian Neuhauser attended First Friday at Rep. Tom Murt's Office in Hatboro, PA to promote TS awareness. He displayed a TS fact board and raised funds by setting up a "make your own bracelet" station for donations.

Thor Watson is designing a kid's website to be linked to our website for his senior project.

The National Society of Leadership & Success, Sigma Pi, Westmoreland County Community College Chapter held a fundraiser in the form of a raffle to benefit the PA-TSA.

Billy Uditsky is a member of the National Honor Society at Hill Top Preparatory School. He worked in the school store and donated his proceeds to PA-TSA.

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Improving Executive Function Skills

An Innovative Strategy that May Enhance Learning for All Children

by Mitzi Waltz

Janie did well in school until she got to fourth grade. Then her grades dropped, she couldn't keep up with her work load, she got frustrated, and her self-esteem was sinking. Janie was referred for testing for special education, but she scored well on the assessments. What was wrong? Janie's difficulties in school stemmed from executive function (EF) weaknesses. Janie is not alone. While children who have learning disabilities, autism, ADHD, traumatic brain injury, and conduct disorder often have difficulties with EF, more children without disabilities are exhibiting EF problems as well.

While definitions vary, EF generally refers to the cognitive processes that enable individuals to engage in goal-directed or problem-solving behaviors. Thus, EF may include goal setting or identifying a problem, developing a plan, the ability to execute the plan, flexibility, attention and memory systems to guide the individual (e.g., working memory), and evaluation or self-monitoring.

Some are now recommending that all children be taught EF processes systematically starting in the elementary grades. One reason is that even in early elementary grades teachers are requiring students to complete long-term projects, as well as lengthy reading and writing assignments—all of which require EF, says Lynn Meltzer, co-founder and co-director of the Institute for Learning and Development and professor at Tufts University. A second reason is that in today's technologically reliant society, students often turn to the Internet or other technology for information.

"We live in an Internet-driven society," says Meltzer. "Students are not taught from information that is pre-organized by experts...it is critical that every child is taught these kinds of strategies. They impact all aspects of student work as they move up in grade levels. Students must coordinate multiple subskills in second grade."

While all students benefit from instruction in EF strategies, such instruction is even more critical for students with disabilities. Research has shown that students with cognitive disabilities and behavior disorders often have weaknesses in EF. With explicit instruction, these students may develop the EF skills, which can help them progress academically and socially.

How Effective Is EF Training?

At this point, research on EF training is still limited. Torkel Klingberg, a neuroscientist at the Karolinska Institute in Sweden, and his colleagues conducted a study of children with ADHD. They found that better working memory skills may reduce ADHD symptoms. In another study, children trained in the EF skill of selective attention were quicker to respond than the control group. These results suggest that EF training may affect the way children's brains develop. However, there is much to learn in this area. For example, the brain's adaptations in response to EF training may be gradual and accumulative, and training may be needed for an extended peri-

od of time. Also, EF training would need to continue to challenge children's skills.

What Happens When EF Is Weak?

Difficulties in EF have long-ranging consequences. Some obvious effects of EF impairment includes children's ability to organize materials, plan long-term projects, manage time, and persist in accomplishing an academic goal such as a term paper or reading a long book. EF weakness also makes it difficult for students to start and complete tasks, and their ability to handle frustration is compromised.

EF problems also manifest themselves in academic tasks such as reading or writing an essay, state Meltzer and Kalyani Krishnan in *Executive Function in Education: From Theory to Practice*. Some of the EF processes involved in reading include 1) drawing on prior knowledge as students shift from "retrieving and interpreting background knowledge to attending to and interpreting print and new content," 2) flexibility as students interpret words, draw inferences, and process redundant information, and 3) prioritizing as students decide which parts of the text is useful for their purpose. Writing requires students to plan, engage in flexible thinking (paraphrasing the topic), organize, and prioritize.

Students with EF problems may also be poor test-takers. First, they are unable to prioritize which information to study when preparing for the test. As they take the test, they are unable to prioritize tasks, plan responses, or monitor their time.

EF problems can also manifest themselves through behavior problems. Failure to plan, to inhibit behavior despite intentions, and to evaluate can all lead students to act inappropriately, according to Philip David Zelazo, professor at the University of Toronto, in his *AboutKidsHealth* series on EF. For example, some children may act inappropriately, because they do not plan or anticipate the consequences of their behavior. In other instances, children who cannot inhibit their actions may continue to behave inappropriately even when they understand the consequences of those actions; children who have difficulty evaluating may not be able learn from punishment and will therefore repeat inappropriate behavior.

EF and Disabilities

Specific EF impairments appear to affect particular disabilities. Children with learning disabilities have difficulty with numerous facets of EF, according to Meltzer and Krishnan. These include self-regulatory activities such as checking, monitoring, and revising when learning as well as weaknesses in cognitive flexibility, sorting, organizing, and prioritizing information.

"Their (students with learning disabilities) strong conceptual reasoning abilities may not match their output and productivity because of their difficulties organizing and prioritizing numerous details, juggling these details in working memory, and shifting flexibly between abstract concepts and literal details as well as from major



themes to the details," state Meltzer and Krishnan in *Executive Function in Education*.

Some researchers see ADHD not just as a problem of paying attention but as a weakness of EF, says Thomas E. Brown, professor at Yale University, in "ADHD as Executive Function Impairments" in the *Help Group Newsletter*. Hyperactivity or impulsivity could stem from a student's inability to control his or her actions or verbalization, both of which can be manifestations of EF problems, he says. Children with ADHD may also manifest EF impairments that impact organizing, planning, and remembering.

"The core of their problem (individuals with ADHD) is a developmental impairment in being able to manage their mind to focus on tasks they need to do, even when those tasks are not immediately interesting," Brown says in the article.

Meltzer says students with learning disabilities and ADHD share a similar EF problem—information overload.

"These students have information coming into a funnel that needs to be processed and prioritized," she says. "They also have to figure out what is most important, ignore the irrelevant information, and shift from the main idea to details. They can't. The funnel is clogged, and as a result these students can't produce the kind of projects and essays required."

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Fundraiser Fishbien

When Danny Fishbein of Elkins Park became a Bar Mitzvah on October 11th, 2008, PATSA also had cause to celebrate. Danny made PATSA the beneficiary of his *Mitzvah Project*, resulting in close to \$1,500 of donations to the organization from his friends and family. The reason for Danny's allegiance to PATSA: the support and help the organization has provided his family since his brother Adam, 10, was diagnosed with TS in 2005.

In addition to rigorous studies, students at Danny's synagogue, Congregation Kol Ami, are required to complete a Mitzvah (commandment) Project to benefit a non-profit organization. An avid athlete, Danny combined his love of sports with a cause close to his heart. Danny endeavored to run 100 miles to raise \$1,800 (100 x *chai* — Hebrew for "life" and symbolized by the number 18) for PATSA.

"PATSA has done wonders for our family," explains Danny. "They have gone to all of our school meetings, connected us to other families who are struggling with Tourette Syndrome just like us, they have advocated for us with the school district, and have always been there to listen with advice, new information and support. PATSA has helped our family cope with Adam's issues a lot better than we would have without them. I hope the money I've raised can help PATSA aide other families as they've done

for us."

Several months before his Bar Mitzvah, Danny e-mailed his guests to tell them about his project, ask for their help and link them to a Web site where they could follow his progress through a blog. Closer to the date, PATSA added a link to its Web site where guests could contribute directly.

Becoming a Bar Mitzvah is a rite of passage from childhood into adulthood. Through his commitment to the organization that has helped his brother, Danny demonstrated his dedication to his family, his understanding of paying forward good will, and the power of one individual — regardless of age — to make the world a better place. To learn about how you can create a project like Danny's, email him at philaphan828@aim.com.

Congratulations Danny!! PATSA would like to thank Danny and all those who supported Danny in this amazing journey.



The Fishbein Children at Danny's Bar Mitzvah, 10/11/08
(from left to right): Danny, Emma & Adam

Marshal & Tamar Granor, David & Jody Rickel, Howard & Michele Levy, Rachel & Joel Fishbein, Bernard & Marie Granor, David & Ruth Ezekiel, Adam & Beth Share, Bennett & Sylvia Fishbein, S. I. & S. F. Davidoff, Bertram & Bernice Brant, Howard & Charlene Schneider, Bruce & Ellen Asam, Daniel Ezekiel, George & Carol Weinbaum, Charles & Jeri Twigg, Jake & Karla Azachi, Joan & Michael Mahalis, Stacey & Mitchell Jungreis, Risa Ferman, David Flaks, The Hoffmans, Nechama Bernhardt & Michael Field, Barbara Rudnick & Irwin Matusow, The Charendoff Family, Rosalind & David Ingber, and Janine Pratt, Bill Hyman & Family

Youth Ambassador Leadership Training



TSA is once again having a Youth Ambassador Program Training in Spring 2009. The program offers three days of comprehensive training for teen leaders (ages 14 through 19) in the Washington, D.C. or surrounding area. TSA will underwrite the cost of one teen per chapter (which includes hotel accommodations for the nights of the training with any additional nights at your own expense; airfare; training-sponsored meals for youth/parent team; training program materials and ground for related events). Items that are at attendees' own expense include non-conference sponsored meals and expenses

for youth/parent team and airfare for parent/adult guardian.

Each teen must be partnered with their parent or guardian, who will also participate in the training. Chapters can also open training to additional teams, at their own expense (including travel, hotel and program meals and materials), as long as they meet the same qualifications.

The program is open to both teens with TS and those who do not have it. All participants must be committed to the goal of the Youth Ambassadors—promoting awareness, acceptance and understanding of Tourette Syndrome. Applications will be available from local TSA Chapters starting December 1st. Deadline for applications is February 15, 2009.

Diane and Darryl Mallah are sponsoring the training in memory of Diane's mother, Eleanor Wachter.

Administrative Report

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I also would like to recognize the youth that attended our TS awareness days at the capital this year. Chas Tocci, Christian DeVol, Christopher Watson, Brian Neuhauser, Kayla Sloan, Natalie Simms, Demi Simms, Eric Canale, Joshua Canale, Emma Canale, Adam Fishbein, Daniel Kenney, and Ryan Nocero came in support of the PA-TSA. They spoke with legislators about Tourette Syndrome. Some went from office to office giving them information and talking with them about how it feels to have TS and how PA-TSA supports them. What an amazing group of kids.

I have to commend each of you as parents. It is difficult to raise successful children in this society. Each of you has the added responsibility of a child with a misunderstood disorder. You all deserve a pat on the back for going to those school meetings and fighting for your child's rights, for staying up all night with your child because he/she can't sleep (whether it be due to a new tic or anxiety about school the next day), for your patience and understanding, and for your efforts in making your children into caring and responsible adults. Your efforts have shown through your children as they help pave a brighter future for all diagnosed with Tourette Syndrome.

Sabrina Bosse

Letters to the editor

Do you have questions or comments that you want to share?

Are you holding an event that you would like to share with PATSA? Send your questions, thoughts, events, and pictures to our office and we will share them with our readers!

LETTER TO THE EDITOR
c/o PATSA
132 W. Middle Street
Gettysburg, PA 17325

*Please note that your submission may not be selected for the specific issue that you submitted for, due to limited space being available. Thank you.

Success Stories Wanted

Is there a recent accomplishment in your life?

Perhaps someone made the Honor Roll, or someone is Graduating. Is a difficult Project finally completed, or did someone get a New Job? Do you know someone who just deserves to be recognized for the good they do every day?



Share these and other successes with us, and we'll pass them on to our readers! Your accomplishments encourage others to pursue their goals and dreams!

Disclaimer

This newsletter is published four times a year. Opinions expressed in this publication reflect the views of its editor and contributors. They are not necessarily the views of the PA Tourette Syndrome Association (PATSA). While we will attempt to respond to all mail, we are not able to answer medical questions. The PATSA, Inc. does not endorse products, services or manufacturers. Such names appear only as information for our members. PATSA assumes no liability whatsoever for information about or the use of any product or service mentioned. Support group leaders and individual volunteers who have agreed to accept telephone calls concerning Tourette Syndrome are knowledgeable about TS: however, their comments reflect their personal background with TS and do not necessarily reflect the views of the chapter.

OVERCOMING KID'S FEARS ABOUT SCHOOL, SPORTS and BULLIES

New Book Tackles Ways To Overcome Challenges, Teaches Kids Lifelong Coping Skills

FOR IMMEDIATE RELEASE:

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Psychologists agree — the classroom and the school yard can be anxiety-producing for children — at any time of the year. Kids struggle with a wide range of fears — from not being liked, to not being smart enough, to not being picked for a team — or worse, to being teased or bullied.

No one knows the struggle a child goes through better than Jeffrey Feldstein, whose son Noah was diagnosed with Tourette Syndrome, and whose fears were compounded by the disorder. His search for answers to help Noah inspired Feldstein to write *"THERE AIN'T NO CAN'T"* a book which provides innovative strategies, and proven techniques that empowered Noah and helped him achieve goals well beyond his dreams.

With his easy to use success strategies and behavior modification techniques, Feldstein targets children 8-18 and helps them "get what they want from life" with practical ways to overcome challenges and limitations. Using his techniques, Noah has successfully obtained his black belt in Tae Kwon Do, overcome disruptive tics of the body, taken part in a children's triathlon and achieved many more victories by utilizing the simple steps in the book.

Feldstein shows readers how to accomplish just about anything with simple, easy techniques. Among his tips are how to identify what you really want, why you haven't gone after it, how to motivate yourself to do more, how to move forward little by little towards your goals, ways to increase your commitment in getting what you want and how to reward yourself.

Jeffrey and his son Noah are available to discuss this positive, life altering process that can help anyone achieve success, build confidence and can be truly inspirational to others.

WHO: Jeffrey and Noah Feldstein (9-year-old with Tourettes)

WHAT: *There Ain't No Can't: A father's tribute to his son's triumph*

WHY: Kid Helps Kids Overcome Fears

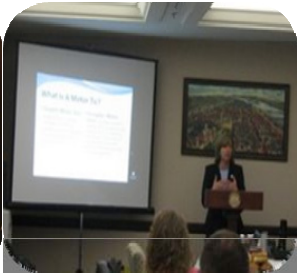
Affecting 1 in 200 kids, (approximately 200,000 people and 28,000 in New Jersey alone), Tourettes is one type of widely misunderstood disorder in the same realm as OCD, Dyslexia, Autism and ADHD. This syndrome can get better or worse, but is a lifelong condition affecting more boys than girls and which develops around the ages of 5-7. The book, *THERE AIN'T NO CAN'T* (www.thereaintnocant.com) is available at online bookstores for \$19.95. All of the proceeds from the book will be used to find a cure for and create awareness of Tourette's Syndrome.

TS Awareness Day at the State Capital

Several families, Legislators and supporters joined the PA-TSA Advocates at the Capital Building in Harrisburg on October 7th 2008. Wireless Zone partnered with PA-TSA in sponsoring this event. Legislators and families were invited to breakfast and a presentation on Tourette Syndrome in the morning. Advocates staffed an information booth in the Capital for the remainder of the day. In addition to the Legislators we spoke with at our breakfast, our family groups were able to visit 58 Legislative offices and held 6 individual meetings with Legislators and their staff to provide information in the needs of individuals with TS within PA.



Breakfast



Presentation



Information Booth

Meeting with our Legislators



Rep. Hennessey, Joyce DeVol, Sen. Dinniman and Christian DeVol



Christopher Watson, Christian DeVol, Brian Neuhauser, Rep. Dan Moul, and Kayla Sloan

Improving Executive Function Skills

Continued from Page 1

Children with autism, too, show deficits in EF. Specifically, these individuals have difficulty in planning future actions and cognitive flexibility.

Assessing EF

Assessing EF, especially in children, is a complex task. Just of couple of factors that can skew results are that individuals' results on EF assessments may vary due to their anxiety level or they may perform well on tasks in an assessment setting but not when faced with similar tasks in the real world, especially when novelty is a feature of the situation. Also, it is difficult to parse out one area that is the source of EF difficulty.

That said, some of the assessments used to determine EF ability include:

Stroop Color Word Task—Measures an individual's ability to inhibit responses, resolve interference, and resolve behavioral conflict.

Go-No Go Task—Measures an individual's attention, flexibility of responding, and ability to withhold a response.

Stop-Signal Task—Measures an individual's ability to stop a response that is already underway.

Tower of Hanoi—Measures an individual's ability to plan ahead.

Wisconsin Card Sorting Test—Measures an individual's ability to test hypothesis and flexibility.

Strategies to Strengthen EF

Though EF strategies can—and often are—taught in one-on-one settings or in small groups, some recommend that all students be taught EF strategies in general education classes.

"We need to teach executive function strategies so students can plan, organize, prioritize and use their working memory effectively," says Meltzer. "Then students become efficient and successful; their self-esteem improves and their effort becomes more goal-oriented. All students benefit from the strategies, and some students must have them. If we embed the strategies in the curriculum, all students benefit."

A few models of classroom-based EF strategy instruction are available, including the Kansas intervention model, Benchmark model, and Drive to Thrive, according to Meltzer in her book, *Executive Function in Education*. All of these models share common principles:

Strategy instruction should be directly linked to the curriculum.

The strategies should be taught explicitly, including teacher modeling and extensive practice.

Strategies should be taught in a structured, systematic way.

Strategy instruction should address students' motivation and effort.

One way to implement the above is for educators to teach a strategy a week, says Meltzer.

As a follow up, create a "Strategy of the Week Board," on which students post their favorite strategy. This also creates a springboard for a discussion of the strategies.

However, EF strategies are not a "one size fits all." For students to use EF strategies effectively, as a first step they must understand their own learning profile and their strengths and weaknesses as well as which strategies work for them, according to Meltzer.

"You need to teach the strategies for the school and classroom, as well as for the individual child," she says. "Then you help students become metacognitive learners who can understand how they learn."

Examples of EF Strategies

Special educators already use many of the strategies that help students improve EF, such as checklists and "how to" lists, breaking long assignments into chunks, and using visual calendars, time organizers, and mnemonics.

Meltzer takes these strategies a step further. Some examples from *Executive Function in Education* are:

Memorization—When using acronyms to help students memorize information, the "crazier the phrase," the better. If a student is non-verbal, then make a cartoon.

Cognitive Flexibility—To help students improve cognitive flexibility, work with riddles and jokes to help students shift between word meanings. In math, students can ask themselves: do I know another way to solve this problem, does this look similar to other problems I have seen, is this problem the same or different from the one before it?

Prioritizing—To help students prioritize information, teach students to listen to the teacher's intonation during lectures. Also, students can highlight the most important ideas in a text in one color and details in another color.

Notetaking—To help students prioritize and remember information students can take 3-column notes: the first column contains one word that is the core concept, the second column contains the details supporting the concept, the third column contains the strategy the student will use to remember the information. When taking notes from text, students can use a 2-column approach. In the first column, students ask themselves questions about the text, and they put the answers in the second column.

Self-Monitoring and Self-Checking—Helping students check their work requires two processes: 1) Provide explicit checklists for assignments, so students know what to check for, and 2) Help students develop personalized checklists, so they become aware of and check for their most common errors. As a final step, students can make their own acronyms to remind themselves of their personal error traps.

Resources

Executive Function in Education: From Theory to Practice, editor, Lynn Meltzer

National Center for Learning Disabilities, <http://www.nclld.org/content/view/865/391/>

Center for Research on Learning, Strategies Intervention Model, http://www.specialconnections.ku.edu/cgi-bin/cgiwrap/speconn/searchabledb/moreinfo.php?desc_id=154

Tools of the Mind, <http://www.devcogneuro.com/research.html#ongoing>

Language, Speech and Hearing Services in Schools, Vol. 30, 265-274, "What Are Executive Functions and Self-Regulation and What Do They Have to Do with Language-Learning Disorders?," <http://www.architectsforlearning.com/sitebuilder-content/sitebuilderfiles/singerbashir1999.pdf>

Changes in PA Education Law Adopted with the Budget (7-4-2008)

The following changes in Pennsylvania education law were adopted by the Governor and General Assembly along with the annual budget on July 4, 2008. These changes can be found in House Bill 1067.

Public School Funding Formula and Accountability Plans

The state establishes a new funding system for public education and fiscal accountability requirements for use of the additional funding. See other ELC fact sheets for details.

High School Graduation Tests

Background: Since 2007 the Governor and the State Board of Education have been working to create new, high stakes graduation tests. Students would have to pass the new tests in order to get a diploma and graduate from high school. Earlier in 2008, the state Senate voted for a bill that would have prohibited these new tests. The House of Representatives did not pass this bill, but wrote public comments criticizing the tests.

New Law Adopted July 4: Section 2 of House Bill 1067 says: "Prohibition of Certain Regulations for the 2008-09 Fiscal Year — Notwithstanding any provision of law to the contrary, in the 2008-09 Fiscal Year, a regulation to change or establish high school graduation requirements shall not be further promulgated, approved or proposed."

The 2008-09 Budget adopted by the Governor and General Assembly includes \$23 million in additional funding to develop new graduation tests.

What does all of this mean? First, the Governor and the Secretary of Education will hire and pay companies to develop the new graduation tests during 2008-09. Second, the State Board of Education will continue working on official regulations establishing the tests, but will delay adopting the final regulations until after June 2009. New graduation standards will not go into effect during 2008-09 and students will continue taking the current tests (the PSSA). There will be a lively debate during 2008-09 about whether Pennsylvania needs more student assessments and new standards for high school graduation.

How can you get involved? Contact the [State Board of Education](#) and your [state legislators](#).

Student Bullying

The PA Office for Safe Schools may make grants to public schools for programs to reduce student bullying.

Every school district and charter school must adopt a policy against student bullying. The policy must include disciplinary consequences for bullying and identify school staff who will receive bullying reports. The policy may also provide for prevention, intervention, and education programs on bullying. Bullying is defined to include student actions directed at another student that create a threatening environment, substantially interfere with a student's education, or substantially disrupt the orderly operation of the school. Bullying may include student actions either in school or out-of-school. Such actions must be severe, persistent, or pervasive and may be written, verbal, physical, or electronic.

Compulsory School Age in Philadelphia

The School District of Philadelphia may set its compulsory school age at no earlier than age 6.

Student Discipline Records

Current law requires public schools and charter schools to transmit the disciplinary records of a transferring student to the student's new public or charter school.

This requirement is now expanded to require transmission of disciplinary records when students transfer into a nonpublic school.

Charter Schools

Many changes were made in charter school laws, including:

School districts are prohibited from placing a cap on student enrollment in a charter school or cyber charter school without the school's agreement. This prohibition applies to past, present, and future charter school contracts.

Charter school administrators are "public officials" subject to ethical standards and financial disclosures, and shall not receive compensation from another charter school or related company.

Charter schools are now eligible to apply for state alternative education funding if they provide these services to a school district. Such applications must include written support from the school district.

The Philadelphia School District may renew a charter school for a single one-year period instead of the normal period of 3-5 years, in order to gather additional information about the school's academic performance. This one-year decision shall not be renewed or appealed. The Philadelphia School District may allow a charter school to operate at more than one location.

The Philadelphia School District may require charter schools in corrective action status under NCLB to meet student achievement targets and conditions in order to avoid revocation of the charter.

Pittsburgh School District

May sell unused property and buildings without the normal process involving sealed bids and may also convey such property to an urban redevelopment authority.

Philadelphia School District

Must file a report about the operation of and plans for schools operated under agreements with outside entities pursuant to 24 PS 6-696(i)(2). This report must be filed by September 1, 2008 and annually thereafter with the Department of Education.

Classroom Placement of Twins

With some exceptions, schools must now agree to parental requests to place their twins in either the same or different classrooms.

Virtual High School Study Commission

The General Assembly forms a Study Commission to examine the feasibility and costs of creating a state-operated, internet-based high school for students throughout the Commonwealth. The Commission may design all aspects of the school and issue its report by the end of 2009.

WHAT CAN YOU DO IF YOUR CHILD WITH A DISABILITY IS BEING HARASSED BY OTHER STUDENTS?

IMPORTANT: ELC's publications are intended to give you a general idea of the law. However, each situation is different. If, after reading our publications, you have questions about how the law applies to your particular situation, contact us for a referral, or contact an attorney of your choice.

CAN HARASSMENT OF MY CHILD BY ANOTHER STUDENT BE ILLEGAL?

"Peer-on-Peer" harassment (name-calling, written statements, or physical abuse) of a student with a disability can be illegal. If another student has seriously intimidated or engaged in abusive behavior toward your child because of your child's disability, and the school district, after notice to the principal or other school leader, does not take steps to fix the problem, the school district could be in violation of the law. Every negative encounter with another student does not present a legal issue. Illegal disability harassment must be continual and repeated. It must also be severe, persistent, and pervasive enough to make it difficult for a student to learn or take part in school activities or, if a student with a disability, to make meaningful educational progress in her educational goals. Federal, state and local laws protect students with disabilities from excessive harassment in school.

If your child is receiving special education, he or she may have additional rights. If your child's learning has been made very difficult because of "peer-on-peer" harassment, his or her right to a "free and appropriate" education may have been violated. This can be true even if the harassment is not focused specifically on your child's disability. The school district must offer your child a special education program that allows him or her to make reasonable progress, and a school and class at which learning can take place. If harassment from other students is making learning extremely difficult, the situation may violate the federal special education laws. Keep all correspondence from you to school personnel and from the school back to you, and keep a record of all phone calls. Also keep records of the impact of the harassment on the child, such as decline in grades, the need for counseling, etc.

WHERE CAN DISABILITY HARASSMENT OCCUR?

Disability harassment can occur anywhere connected with school: in classrooms, in hallways, on the school bus, and in cafeterias. It can also occur during school sponsored activities on school grounds or at other locations.

WHAT CAN I DO IF MY CHILD IS BEING HARASSED?

Your school district is responsible for taking reasonable steps to see that your school is safe for

your child. Your first step should be to explain the problem to the teacher to see if the matter can be resolved quickly. However, if the harassment is severe, or if the teacher doesn't fix the problem promptly, it is important to contact a school leader such as the principal or the superintendent in writing. Explain what is happening to your child in detail, including who was involved, who witnessed the incident, what happened, and when and where it happened. You should also make a written record of all incidents and send copies to the principal and the district superintendent. Ask the school district to respond to you in writing.

You should also ask the school district to convene an IEP Team meeting. The IEP Team meeting will let you tell school officials what is occurring, and will let the IEP Team review your child's IEP and make sure that the school is taking steps to end the harassment. You should be prepared to tell the IEP Team what you think would work, and how the school can use its existing or other resources (e.g., bullying/violence prevention programs, school therapists, guidance counselors, etc.) to end the harassment of your child and to prevent it from recurring. If the harassment has caused your child to miss school, you might ask for compensatory services. If your child now needs counseling or other support services, you should discuss adding them to the IEP.

WHAT CAN I DO IF THE HARASSMENT DOES NOT STOP?

If the disability harassment has been on-going (that is, there have been repeated incidents); you have put school staff, including the school leaders, on notice; and the school staff has sat by while the harassment occurred and was repeated, the school district may be violating federal, state and/or local laws that entitle eligible students with disabilities to a free appropriate public education and protect them from discrimination. Under these laws, you can challenge your child's IEP through the Special Education Procedural Safeguard System and/or file a complaint with the Pennsylvania Human Relations Commission or the Office for Civil Rights. You may also be able to sue your district in court. If you are considering filing a lawsuit, you should contact an attorney to make sure that you have a good harassment claim and that you are suing within legally mandated timelines.

Pennsylvania's Special Education Procedural Safeguard System includes a pre-hearing conference with school officials and a formal hearing before an impartial hearing officer. An appeal and court action may also be an option. For more information on how this system works, please see the Education Law Center's fact sheet "Resolving Special Education Disputes" which is available from our website and phone numbers listed below.

Continued On Page 6



PROJECT CONTACT

The following individuals have agreed to accept telephone calls concerning Tourette Syndrome. Although all phone volunteers are well versed in TS, their comments reflect their personal background with TS and do not necessarily reflect the view of the chapter. If your county is not listed please contact the PATSA for further information. Information is listed by Pennsylvania County.

ADAMS

PATSA Office
717-337-1134

ALLEGHENY

Jay Goodman
412-818-6009

Diane Tifone
724-492-8794

BERKS

Susie Lutz
610-562-8785

BUCKS

Colleen Rilling
215-702-8272

Mary Brennan
215-860-1325

Paula Wilson
215-956-1662

CHESTER

Lesley Geyer
610-409-0833

Becky Nuttall
610-225-0457

Bonnie Uditsky
610-449-3240

CLINTON

Karen Spies
570-322-7754

COLUMBIA

James Zandarski
570-752-3355

CUMBERLAND

Rick Rubin
717-236-3941

DAUPHIN

Rick Rubin
717-236-3941

William O'Sick
717-561-1052
Laura Umbrell
717-263-5745

DELAWARE

Lesley Geyer
610-409-0833

Becky Nuttall
610-225-0457

Bonnie Uditsky
610-449-3240

ELK

Tim Piccirillo
814-772-1291

ERIE

Jane Vogel
814-739-9330

Nichole Burlingame
814-787-4067

FRANKLIN

Laura Umbrell
717-263-5745

INDIANA

Lillian Mouser
724-726-5740

LACKAWANNA

Wendy Toolan
570-876-0320

LANCASTER

Dawn Smith
717-665-4383

LEBANON

Rick Rubin
717-236-3941

LEHIGH

Eric J. Staib
610-530-0541

LUZERNE

Joanne Bayer
570-822-4580

LYCOMING

Gary & Karen Spies
570-322-7754

MONROE

Susan Bohus-Beck
570-676-5331

MONTGOMERY

Lesley Geyer
610-409-0833

Becky Nuttall
610-225-0457

Bonnie Uditsky
610-449-3240

NORTHAMPTON

Neil Adams-Conroy
610-258-9615

NORTHUMBERLAND

Tina Jenkins
570-286-0964

PHILADELPHIA

Sidney Newman
215-673-3261

PIKE

Susan Bohus-Beck
570-676-5331

SCHUYKILL

Joyce Miersky
570-462-1113

WASHINGTON

Jay Goodman
412-818-6009

Saralyn Stockton
724-941-2076

WAYNE

Susan Bohus-Beck
570-676-5331

WESTMORELAND

Vickie Luehm
724-863-3163

Cheryl Walker
724-327-0651

SUPPORT GROUP NEWS

The following support group leaders and individuals have agreed to hold Support Group Meetings regarding Tourette Syndrome. Although all Support Group volunteers are well versed in TS, their comments reflect their personal background with TS and do not necessarily reflect the views of the Chapter. As you can see MANY counties are without a support group causing families to travel long distances to attend a meeting closest to them. If your county is not listed and you are interested in starting a Support Group please contact PATSA for further information. If you are not interested in attending support group meetings but have the need to speak with someone, visit our Contact Page for additional names and counties. Don't forget PATSA is also available to talk and answer questions.

Kids TS Support Group

For: The entire Family

When: 3 times a year February, May, and October

Where: A family outing will be arranged for each date

Contact: Pam Simms -
215-540-8290
psimms23@aol.com

Adams, York, Cumberland & Franklin

For: Children and Adults with TS and their Families

When: 3rd Saturday of each month
2:00 – 3:30 PM

Where: Gettysburg Hospital
Community Room A

Contact: Melinda Bowling -
717-334-4895
ts_support_group_aycf@comcast.net

Mainline: Delaware, Chester, Southwest Montgomery

For: Children and Adults with TS and their Families

When: 2nd Tuesday of each month
7:30 – 9:30 PM

Where: New Seasons Assisted Living
Wayne, Pa 19807

Contact: Eileen Ackler
610-222-4870
acklerfamily@verizon.net
Lesley Geyer - 610-409-0833
lgeyer@comcast.net

Ephrata

Currently not meeting due to no support group leader.

Lower Bucks/Montgomery

For: Children and Adults with TS and their Families

When: 4th Wednesday of each month
7:30 – 9:00 PM

Where: St. Mary's Medical Center
Classroom 2
Langhorm, PA

Contact: Colleen Rilling
215-702-8272
Mary Brennan
215-860-1325

Philadelphia

For: Children and Adults with TS and their Families

When: Every other month
7:00 PM

Where: Evangelical Mannor
Philadelphia

Contact: Wayne and Merle Siegel
215-464-9341
SiegelWD@aol.com

Westmoreland

For: Children and Adults with TS, their Families, and Others

When: 1st Monday of each month
6:00 – 8:00 PM

Where: Arc of Westmoreland Greensburg

Contact: Cheryl Walker
724-327-0651
cwworkshard@alltel.net
Vickie Luehm
724-863-3163
vluehm@aol.com

Upper Perkiomen: Parents of Special Education Students

For: Children and Adults with TS and their Families

When: Several Times Per Year

Where: Upper Perkiomen Red Hill Library

Contact: Phyllis Pepe
215-541-4947
UP.PSES@Verizon.net

Web: <http://PerkiomenParents.org>

Washington and Southern Alleghany

Support group meetings as requested please contact Jay Goodman at 412-818-6009.

Wayne, Pike, Monroe, Lackawanna

For: Children and Adults with TS and their Families

When: 2nd Friday of each month
6:00 – 7:30 PM

Where: Moravian Church (Basement)
Newfoundland, Pa

Contact: Susan Bohus-Beck
570-676-5331
sqbil@earthlink.net

Mental Health Parity Is Law!

For far too long, the TSA has lobbied for the passage of the Mental Health Parity Act, but today, we are extremely proud to share the good news of passage with you. On October 3rd, The Parity legislation formally known as the **Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008** (HR 1424) has successfully passed with a winning conclusive vote of 263-171 in the House, following the Senate's successful vote of 74 - 25 on October 1, 2008. The bill, signed by President Bush, is now law and will be enacted in early 2009-2010.

The TSA would like to acknowledge and thank its members along with the mental health community. All your hard work has paid off! Your recent telephone calls, letters, and "Trips to the Hill," have made a difference with two of TSA's long standing issues: *Mental Health Parity* and the *Genetic Information Nondiscrimination Act (GINA)*. The TSA commends Congress and the White House for finally making these two bills law.

As you know, the mental health legislation is a bipartisan bill that would make using one's mental health benefits no more restrictive than one's physical health benefits. Below are some brief bullets points of the major provisions to be enacted. Also attached is a summary and TSA's White Paper on Parity.

All financial requirements of coverage, including deductibles, copayments, coinsurance, and out-of-pocket expenses and all treatment limitations shall be the no more restrictive for mental health/substance use disorders as they are for medical/surgical benefits.

Mental health or substance abuse benefit coverage is not mandated, but if mental health coverage is offered, parity must be provided.

If the states have stronger parity laws than the federal, they are able to retain their own (state) parity laws.

It does not apply to employers with less than 50 employees are exempt from this Act, nor does it affect the individual insurance market.

The effective date for most plans is January 1, 2010 to allow for each plan renewal.

However, the fight for equality is not over! We now have an exciting opportunity to ensure this momentum of equality continues to serve our community. Contact your Chapter Liaison to share with them your stories on insurance coverage discrimination and how this law is going to impact you.

At this time, we also invite you to join us in thanking your Members of Congress for finally passing the Mental Health Parity legislation. To send your letters- visit the TSA Website, go to the "Public Policy section," click onto the "TSA Legislative Action Center" and then click where it says Here to take action."

John K. Yi
Legislative Associate
Tourette Syndrome Association, Inc.
Tel: 202-408-7075
Fax: 202-408-3260
e-mail: tadc@tsa-usa.org
<http://www.tsa-usa.org>

In Memory and In Honor Of



In Memory Of

Carlton James Austin, Jr.

From:
Judy Geyer
Ida Geyer
"The Neighborhood Gang"
Mr. & Mrs. Bob Feldbaumer
Mr. & Mrs. Dave Paxson
Mrs. & Mrs. Bud Starr
The Trail Family
William & Charlotte Kuechler
Karen Austin & Family
Anne Edwards
Charles & Mary Messa
Barry Wolf

To donate in loving memory or in celebration of your friends and loved ones, please contact the Pennsylvania Tourette Syndrome Association.

WHAT CAN YOU DO IF YOUR CHILD WITH A DISABILITY IS BEING HARASSED BY OTHER STUDENTS?

Continued from Page 4

To contact the U.S. Office for Civil Rights, call 800-421-3481 or check the website at <http://www.ed.gov/about/offices/list/ocr/index.html?src=mr>. You can also contact the Pennsylvania Human Relations Commission at 412-255-2600 (Pittsburgh office) or at 215-560-2496 (Philadelphia office).

WHERE CAN I GET MORE HELP?

You can get more information on how your school can take stronger steps to prevent bullying and other types of harassment against all students from the Blueprints Bullying Prevention Program website at:

<http://www.colorado.edu/cspv/safeschools/bullying/overview.html>. This is a program designed to reduce and prevent bully/victim problems in school. You can also find information about other prevention programs by calling the Committee for

Children at 800-634-4449 or by visiting their website at <http://www.cfchildren.org>. You can request a free information packet from this site.

You may also find help to prevent or end harassment at the following websites, or by calling the following telephone numbers:

- The American Civil Liberties Union (ACLU) – www.aclu.org. In Pittsburgh, call 412-681-7736 and in Philadelphia, call (215) 592-1513.
 - The Pennsylvania Department of Education – www.pde.psu.edu or 717-783-6788 (this is not a specific department but your call will be directed from this location).
 - Center for Safe Schools – www.center-school.org, click on "Violence Prevention," click on "Center for Safe Schools." You can also reach the Center at 717-763-1661. They deal with a variety of issues such as school safety and violence prevention.
 - Every Child Learning: Safe and Supportive Schools Report discusses issues and recommendations for safe and supportive learning environments. You can order a copy of the report by visiting the Association for Supervision and Curriculum Development website at www.ascd.org or by calling 800-933-2723, ext. 2.
- If you live in the Philadelphia School District, there are other places to turn for help. Contact ELC for a list of such contacts.

Funding for this brochure was provided, in part, by the Disability Rights Network of Pennsylvania (DRN), pursuant to the Developmentally Disabled Assistance and Bill of Rights Act, P.L. 101-496, and the P&A for Mentally Ill Individuals Act, P.L. 99-319. DRN is located at 1414 N. Cameron Street, Suite C, Harrisburg, PA 17103. Telephone: 800-692-7443 or 717-236-8110. Website: www.drnpa.org.

Prepared by: Education Law Center (Rev. 8/07) - (215) 238-6970 (Philadelphia) (412) 258-2120 (Pittsburgh) - www.elc-pa.org

Volunteers

Volunteers Make The Difference

The following people donated their time to perform volunteer work for PATSA.

WE SINCERELY APPRECIATE YOUR HELP!

<i>Eileen Ackler</i>	<i>Joyce Miersky</i>	<i>Gary Spies</i>
<i>Lori Anselm</i>	<i>Lillian Mouser</i>	<i>Karen Spies</i>
<i>Neil Adams-Conroy</i>	<i>Sidney Newman</i>	<i>Eric Staib</i>
<i>Joanne Bayer</i>	<i>Becky Nuttall</i>	<i>Saralyn Stockton</i>
<i>Susan Bohus-Beck</i>	<i>William O'Sick</i>	<i>Diane Tifone</i>
<i>Melinda Bowling</i>	<i>Phyllis Pepe</i>	<i>Wendy Toolan</i>
<i>Mary Brennan</i>	<i>Jakob Petitto</i>	<i>Nancy Tyler</i>
<i>Nichole Burlingame</i>	<i>Tim Piccirillo</i>	<i>Laura Umbrell</i>
<i>Jay Goodman</i>	<i>Colleen Riling</i>	<i>Bonnie Uditski</i>
<i>Leslie Geyer</i>	<i>Michael Serratore</i>	<i>Jane Vogel</i>
<i>Tina Jenkins</i>	<i>Merle Siegel</i>	<i>Cheryl Walker</i>
<i>Vickie Luehm</i>	<i>Wayne Siegel</i>	<i>Paula Wilson</i>
<i>Susan Lutz</i>	<i>Pam Simms</i>	<i>James Zandarski</i>
<i>Debbie Massa</i>	<i>Dawn Smith</i>	

PATSA is always seeking volunteers!!!!

Acknowledgement of Thanks

PERSONAL AND CORPORATE BENEFACTORS

*Wireless Zone Foundation for Giving
Covenant Presbyterian Church's Members' Mission Money
Immaculate Heart of Mary's Knights of Columbus 13692
Thomas Murt*

The clients, Board of Directors and staff of the Pennsylvania Tourette Syndrome Association would like to express their appreciation to these individuals and organizations that have supported our Association. Your kindness and generosity is greatly appreciated. If we have missed anyone please contact PATSA and your name will be mentioned in our next newsletter.

TICcing IN PUBLIC

8 Smart Ways to Deal with It

by Mitzi Waltz

1. Medical ID Card/Bracelet

When you were a kid, your mother might have carried one of those medical identification cards that the Tourette Syndrome Association sells. Remember those? Some stranger would make a rude remark, or you'd be having a visible/audible tic in the grocery store, and mom would flash the card. It might have helped you both in some situations.

If your tics are quite severe, one of these cards in your wallet is probably still a good idea, just in case someone seriously misinterprets your movements or sounds. It's not for flashing at random strangers, though (and you might prefer a Medic-Alert style bracelet or pendant for more difficult situations).

For your public outings, we suggest seven more methods for coping with tics that won't stay in the closet when you're out and about:

2. Don't isolate yourself

It's tempting, especially if you get nasty remarks and curious looks, but you've got as much right to enjoy public spaces and places as anyone else. In totally public venues like the local library, the swimming pool, the shopping mall, or the sidewalk, don't worry about doing anything special. These places belong to everyone, and that includes you. Some "public" places are a bit different, because other people come to them with certain expectations: upscale restaurants, the opera, that sort of thing. For these rare exceptions, see below.

3. Bring something attention-absorbing

When your mind is totally focused, your tics tend to recede. Waiting around in a public place might cause tics to come to the forefront. Always carry a book of really hard crosswords, number puzzles, a hand-held computer game, needlework, sketchbook, an iPod with the ultimate party mix, or something similarly engrossing, and let yourself really get absorbed by it. Not only are you less likely to tic, but you won't even sense it if you do, and you won't observe any stares from other patrons either.

4. Bring a friend

If you're enjoying their company and they're enjoying yours, it will put strangers around you at ease. They may notice your tics, but they'll also notice that you're obviously a normal guy or gal with friends who like you. It's an automatic icebreaker.

5. Be prepared

Think about your current tics, and how you might minimize both your own discomfort and others' potential reaction. For a spitting tic, bring a handkerchief so you can be discreet about it. If you're sniffing loudly, try a bit of Vick's VapoRub or similar strong-smelling ointment under your nose — it will change the sensation, quite possibly short circuiting the tic for a while. If you have complex tics that slow you up, allow extra time to get into and out of events. If you find that you're better relaxed after an hour at the gym or yoga class, schedule your life accordingly. And so on...

6. Prepare others

For events where the noise level might not be high enough to camouflage vocal tics, contact the venue in advance to see if they can suggest a solution. Perhaps a private box can be arranged (and if it's a disability accommodation, there really shouldn't be any extra cost to you...). Many movie theatres now have "VIP Seating" for people who like to talk and canoodle during movies, and "Cry Rooms" for people who want to bring babies. These facilities can be helpful for you too.

7. Frame your response

If someone goes out of his way to be rude, use your judgment, but don't be shy about defending your rights. You can reply directly with an explanation, complain to the management of the venue, or take your business elsewhere. The only thing you shouldn't do is take it personally. You can't control your tics, but you can raise the level of the dialog, and, just maybe, add to someone's knowledge.

8. Seek opportunities

Look for places where you can really let go: if you're a (young?) rocker, head for loud clubs, rock concerts, that sort of thing. Other activities to explore include running, skiing, swing dancing, swimming, bicycling—all provide wonderful energy outlets. (For quieter fun times, there are always TSA Conferences and events).



Raising Funds For PA-TSA

During the 2008 Fall Homecoming activities, the Student Programs Office at Millersville University organized its annual Charity King & Queen competition. This year they had 12 candidates who raised funds for 10 different charitable organizations. Each candidate was a student and a member of an organization on campus.

The Charity King/Queen competition is a regular service project for the students and organizations at Millersville and we are pleased that the Pennsylvania Tourette Syndrome Association was selected by Dorothy Kenyon, representing Phi Sigma Pi, to receive funds donated during the competition. \$619 was raised through the efforts of Dorothy Kenyon and Phi Sigma Pi! Thank You



Wireless Zone has paired up with PA-TSA!

We are pleased to announce that the PA Tourette Syndrome Association has formed an alliance with Wireless Zone. Headquartered in Middletown, Connecticut, Wireless Zone is the largest independent cellular agent in the country, with over 260 locations from Maine to Virginia, the Midwest States, and Florida. Their ambitious expansion plans call for reaching 400 stores by 2009. Wireless Zone stores sell a total cellular solution, specializing in the sale of Verizon Wireless Voice and Data Services. Presently Wireless Zone has over 2.5 million customers nationwide.

Wireless Zone Foundation for Giving has committed to donating a percentage of every activation and upgrade done at a Wireless Zone store in the Philadelphia market with specific funding matched by Automotive Technologies, Inc., parent company of the franchise system.

If your needs include a Verizon cellular product, we encourage you to think about Wireless Zone. Your business with a Wireless Zone within the Philadelphia market translates into additional funding for the PA Tourette Syndrome Association!

We would like to thank Adam Anolik for aiding in this wonderful partnership with Wireless Zone.



The Neuhauser Family attended First Friday at Rep. Tom Murt's Office on November 7th in Hatboro, PA to promote TS awareness. Bryan and his mother, Marilyn, displayed a TS fact board. They raised funds by setting up a "make your own bracelet" station and asked for donations. Bryan (pictured above) and Marilyn were on hand to answer questions. They raised awareness and \$54.00!

BEQUEST

Is there room for PA-TSA in your will?



The PA Tourette Syndrome Association relies on community support for over half of our yearly budget. PA-TSA is the sole source provider for individuals with TS in the state of Pennsylvania. Providing free information, education and advocacy service to all. Please help us continue the wonderful work that was started over 20 years ago.

By including PA Tourette Syndrome Association in your will, your gift will support individuals with TS in perpetuity.

For more information please contact Penny at 1-800-990-3300.



PATSA DONATION FUND

Your tax-deductible donation will help toward the funding of expenses related to our services and efforts to serve those in need. The more you give, the more we can do.

Send your donation to:

PATSA

132 West Middle Street
Gettysburg, PA 17325

Please designate your tax-deductible donation to one of the following: GENERAL, ADVOCACY, IN HONOR OF, or IN MEMORY OF.

Donations can also be made using Click & Pledge secure On-Line Donation System on our website at:
www.PATSAInc.org

2009 PA Tourette Syndrome Conference

Save the Date

July 13-14 2009



Our 3rd Annual conference will begin on Monday July 13th with an evening pool party social. Tuesday July 14th will be a full day of activities starting with a Family Challenge Course in the morning and separate trainings and activities for parents and children in the afternoon. Our day will end with a relaxing Barbeque.

For attending professionals, we are planning a 1/2 day program beginning in the morning of July 14th. Look for more specifics in our next newsletter!



WE HOPE TO SEE YOU THERE!!



2009 Calendar

*The 2009 PA-TSA Calendar is finally here!
Order yours today, as supplies are limited.*

These are just three examples of our 12 great artists.



Mail portion below

Name: _____ Qty. _____ \$12.00 EACH _____
Mailing Address: _____ S/H add \$1.50 per calendar _____
Total due \$ _____

For credit card orders visit: <http://www.patsainc.org/cubecart/>