

A PUBLICATION OF THE TOURETTE SYNDROME ASSOCIATION OF OHIO

TSA of Ohio is a non-profit organization whose mission is to identify and serve the needs of persons dealing with Tourette Syndrome in Ohio and Northern Kentucky by education, advocacy, and research.

# Tic-ertape

August 2008

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P.O. Box 28345, Columbus, OH 43228-0345 . 1-800-543-2675 . 614-539-1795 (Columbus Area) . www.tsaohio.org

Volume 25, Issue 4

## Sign up now for TSA Ohio Conference 2008

### Program and speakers

Saturday, October 18, 2008

Children's Institute for Pediatric Education

Columbus Children's Hospital, 700 Children's Drive, Columbus OH 43205

**8:30 to 9 a.m.**

Registration/Continental breakfast



**9 to 11 a.m.:**

**Kathie Snow**, author of "Disability is Natural": "Disability is Natural and Other Revolutionary Common Sense": Like gender, ethnicity, and other traits, disability is one of many natural characteristics of being human. What can happen when we deconstruct disability, use People First Language, and

focus on people's strengths and abilities? Tremendous change is possible when we think and talk differently.

**1:15 to 2:45 p.m.** (Choose one):

"Living Real Lives," Kathie Snow: Self-determination skills can be learned naturally when we ensure people with disabilities have ordinary experiences and opportunities in inclusive settings.

"Obsessive Compulsive Disorder, Description and Assessment," **Beth McCreary, Ph.D.**, adjunct assistant professor, Ohio State University: Defining OCD, differentiating it from other syndromes and diagnoses, and describing the different subtypes within the disorder. Contributing factors to the disorder will be overviewed.



**11 to 11:15 a.m.:** Break

**2:45 to 3 p.m.:** Break

**3 to 4 p.m.** (Choose one):

"Inclusive Education and Beyond," **Kathie Snow**: Inclusion and IDEA, characteristics of an inclusive school, improved parent educator partnerships, effective IEPs, using activity-based goals, cooperative advocacy, etc.

"Obsessive Compulsive Disorder (OCD): Cognitive-Behavioral Treatment," **Beth McCreary**: How cognitive and behavioral principles are applied in the treatment of OCD in adults and adolescents. The concept of exposure and response prevention will be defined and illustrated with several different subtypes of OCD. Treatment-related resources and general information about medications useful in treatment will be noted.



**11:15 a.m. to 12:15 p.m.:**

**Dr. Donald Gilbert**, director of the Tourette Syndrome Clinic at Cincinnati Children's Hospital Medical Center, with an update on medical treatments and research, including genetics, neuroscience, PANDAS, medication and habit reversal. Dr. Gilbert will take questions, and may be available through lunch for further questions and answers.

**12:15 to 1:15 p.m.:** Lunch

### REGISTRATION FORM

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_

STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

E-MAIL: \_\_\_\_\_

PHONE: \_\_\_\_\_

**Fee: \$50 per person.** Lunch will be provided. **Registration is due Oct. 10, 2008.** Scholarships are available.

Make checks payable to **TSA of Ohio** and mail to **P.O. Box 28345, Columbus OH 43228.**

You may also register online at **www.tsaohio.org**. Click on **Conference Info**.

**Continuing Education Units are available for teachers and nurses.**

**TOURETTE SYNDROME ASSOCIATION OF OHIO**  
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## Printed Tic-ertape will carry charge after this edition

### Subscription form

Please sign me up to continue to receive the printed version of the Tic-ertape newsletter twice a year. Enclosed is my \$5 payment to cover printing and mailing expenses.

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**Send this form to:**

TSA of Ohio, P.O. Box 28345, Columbus, OH 43228-0345.

**All material in the printed newsletter will continue to be available for free online at our website, www.tsaohio.org.**

The issue of the Tic-ertape that you are holding is the last printed edition of our newsletter that we will be distributing on a regular basis at no cost to readers. All news regarding the Tourette Syndrome Association of Ohio will be sent out primarily via our website and e-mail from now on.

We deeply regret having to take this step, but serious financial challenges are forcing it. Printing and mailing the Tic-ertape has been one of the TSA of Ohio's biggest expenses, and the number and amount of donations have recently dropped dramatically.

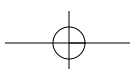
We plan to continue to expand our website's offerings as a far more cost-effective way of getting information out. Furthermore, anyone who wishes to continue to receive a printed Tic-ertape twice a year may do so, for a nominal cost of \$5 to cover the cost of printing and mailing. If you wish to subscribe to the printed edition, please fill out the coupon next to this article and mail it to our headquarters in Columbus.

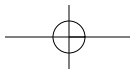
Again, we deeply regret having to take this step. Thank you for understanding.

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## ABOUT TSA OF OHIO

The Tourette Syndrome Association of Ohio (TSAO), a chapter of the National TSA, provides support to those with Tourette Syndrome in Ohio and Northern Kentucky. Dedicated volunteers and staff (Debbie Meyer, administrative coordinator, and Denise Cowan, clerical assistant) publish a newsletter; distribute literature; provide information, referrals, training, phone support and advocacy; sponsor support groups; and promote awareness. Grassroots services in 16 geographic areas are coordinated by Area Representatives. TSAO is governed by a volunteer Board of Directors and benefits from the expertise of Medical and Professional Advisory Boards. It is funded by private contributions and fund raising, relying heavily on its supporters for its continued success. Individuals and families who have obtained a TS diagnosis are asked to contact TSAO to be entered in the database and obtain basic information. After that, the family will be referred to the Area Representative regarding further needs; they may also be asked if they are interested in learning more about how they may be able to help others in their area deal with TS issues. TSAO requests that those who receive try to give back to others in some way when they are able, through volunteering and/or financial support – these are crucial to the success of the association's mission.

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## President's Corner

By Susan Stull  
TSA Ohio  
President



With back-to-school just around the corner, I would like to remind everyone this is the time of year to schedule an in-service at your child's school. Our chapter has many trained in-service providers who travel to the schools free of charge to educate the staff about TS.

I would also like to repeat that this is the last copy of the Tic-ertape

we will be mailing at no charge to readers. If you would like to continue to receive this newsletter by mail it is imperative you return the coupon on the front page to our office. Our Ohio chapter has had a difficult time in the past year making ends meet. As the economy has changed, so have our donations. One way to cut costs is to send our newsletter electronically, but we will still mail out copies for a nominal fee. We will continue to bring you information and updates on TS, but it will be by e-mail or on our website.

And lastly, I would like to encourage all of you to attend our

annual conference on October 18. I had the pleasure of attending a previous conference where our keynote speaker, Kathie Snow, was presenting. I was impressed with her positive and timeless message for people with disabilities. We will again have the pleasure of Dr. Don Gilbert's expertise as he imparts TS updates, and we will also be welcoming Beth McCreary, Ph.D. to speak about OCD and its impact on the lives of people with TS. Our conference is one of the most important events we provide for our members, and I hope all of you will be able to join us.

## Our support groups

What would we do without them? In getting help for the challenges that Tourette Syndrome presents, nothing beats the face-to-face payoffs of speaking to others who have "lived our lives," rather than talking with doctors who, although knowledgeable about the medical aspects of TS, have second-hand knowledge of what it's like living with the disorder.

Following is a listing of TSA of Ohio authorized groups having regular meetings at the present time. If you are interested in starting a group in your area, or would like more information about the existing groups, please call (800) 453-2675 or (614) 539-1795.

### ALLEN COUNTY

Call for information  
Contact: Jennifer Fletcher  
2550 Hall Drive  
Lima, OH 45806  
(419) 516-4130

### FRANKLIN COUNTY

First Sunday of the month  
7 to 9 p.m.  
Call for information  
Contact: Sandy Bowen  
2749 Fairfax Drive  
Columbus, OH 43220  
(614) 538-1177  
shallcross30@aol.com

### GUERNSEY COUNTY

Last Saturday of the month  
6 to 8:00 p.m.  
Byesville Park  
Contact: Melinda Masters  
61770 Byesville Road  
Cambridge, OH 43725  
(740) 680-1367

### HAMILTON COUNTY

(and Northern Kentucky)  
St. Elizabeth South Medical Center  
10 a.m. to noon Sept. 20  
Contact: Lori Caldwell  
59 Windfield Way  
Florence, KY 41042  
(859) 371-5192  
loricaldwell@fuse.net

### LICKING COUNTY

Conference Room at Newark City Schools  
Administrative Services  
Call for information  
Contact: Eva Marino  
85 E. Main St.  
Newark, OH 43055  
(740) 670-7060  
emarinol@laca.org

### SUMMIT COUNTY

Third Thursday of the month  
7 to 9 p.m.  
Children's Hospital, Akron  
Contact: Dorene Shoff  
(330) 745-9571  
dorene4@neo.rr.com

### TRUMBELL COUNTY

Call for information  
Contact: Angie Timko  
2830 Sandpiper Trail  
Warren, OH 44484  
(330) 647-0653  
amt8385@yahoo.com

## TSA of Ohio gratefully acknowledges the following donations

**In Memory Of:** Dr. Chester Plotkin by Jim and Boots Freeman

**In Memory Of:** Irwin Palevsky by Jim and Boots Freeman

**In Memory Of:** Paul Verban by Mary Torma, Jerry Brove, George and Rose Pasterak, Willie and Jerry Kapron, Barb Paskvan, Mr. and Mrs. J. Davoli, Lillian Zaworski, Emma Stransky, Darlene Vrotsos

**Contributions:** William and Janie Melvin, General Electric Evendale Plant, Beta Eta Chapter 3409 of ESA, Velda Smiley, Gamma Kappa #4245 of ESA, Delta Gamma Chapter of ESA, Dale and Anna Geisel, Denise Amato, Hal and Dana McCoig, Rocky and Debra Belcher, Jeff and Karen Hartman

### Pledges:

**United Way of Central Ohio:** Lisa Fraser, James Pepper

**Metro-Cincinnati CFC:** Barbara Parks, Wanda Broach

**State of Ohio CCC:** Robert Hobart, Catherine Simerl, William Cochensparger, Catherine Hanson, Lorrie Dunn, Mary Walcutt, Jill Draper, Katherine Baxter, Marc Smith, Joseph Iannaggi, Amy Goodman, Anita Krivis, Kimberly Mercer, Keith Blosser, Cara Egeland

**Northeast Ohio CFC:** Carol Gundelach, Linda Jones, David Klimkewicz, George Kmetz, John Lewis

**Miami Valley CFC:** James Baker, James Poindexter, Randy Gavney, Thomas Steinbrunner

**United Way for Southeastern Michigan:** Patricia Gaffke

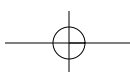
**Heart of Ohio CFC:** Anna Crooks

**OSU Bucks for Charity:** Grace Hurley, Shu-Chen Cheng, Susan Davis, Marsha Fumo, Roger Hamilton, Mary Miller, Colleen Payne, Margaret Skiba, Susan Windle, Mary Wynd

**Contributions to the Mary Lou Bringardner Camp Fund:** Richard and Susan Bringardner

## IMPORTANT REMINDER FROM THE TSA OF OHIO

We neither recommend nor endorse any services noted in the newsletter. Articles are provided for informational purposes only.



# Video games have no place on Brain Pyramid

By Donald Gilbert, MD, MS

Most of us are familiar with the Food Pyramid. Although nutritional research can be contradictory and confusing, there is still general agreement about which foods are healthy for us. Daily intake of fruits and vegetables should always exceed intake of unhealthy items like candy and soda. The Food Pyramid can be viewed online at [www.mypyramid.gov](http://www.mypyramid.gov).

In this column, I would like to present, briefly, a few thoughts on a concept I describe to patients as the Brain Pyramid. The idea behind the Brain Pyramid, like the Food Pyramid, is that there are certain items that are healthy for the brain, like reading, which belong on the pyramid because they make the brain healthy. There are other activities that are OK in small amounts only.

What does this have to do with Tourette Syndrome, ADHD, and OCD? A lot, I would argue.

Nearly every clinic, I am struck by the lack of brain-healthy activities in Tourette Syndrome kids. In fact, I am amazed how often the number one

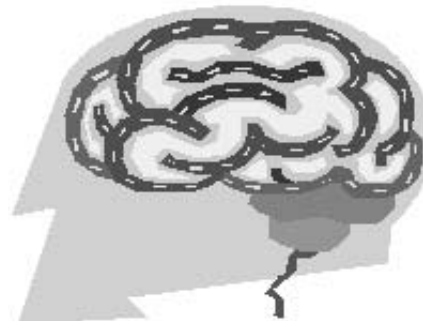


activity is – you guessed it – video games.

Do video games help kids with Tourette Syndrome, ADHD, or OCD gain more frustration tolerance? Do video games improve attention and impulse control? Do video games improve academic performance? In short, should video games be included on the Brain Pyramid?

Science has surprisingly little to say about the effects of video games. One recent controlled study of boys 10-13 by H. Polman et al.

## A Medical View



(Aggressive Behavior, 2008) found that boys' aggression increased after playing violent video games, but not after watching them or playing non-violent games. A study in adults by E.J. Kim (European Psychiatry, 2008) showed video game addiction was more common in persons with more self-centered personalities who had less self-control in other areas. In contrast, it is quite difficult to find any well-designed, replicated studies showing that video games benefit the brain.

So, I would argue that video games do not belong on the Brain Pyramid.

What does science tell us would be on the Brain Pyramid? Many studies show that music changes the brain in positive ways, even in adults. Pursuing musical training in childhood has many benefits for areas of the brain that are affected by Tourette Syndrome and ADHD. Music training even benefits adults.

But for now – if you or a family member are adversely affected by symptoms of Tourette Syndrome, think about the Brain Pyramid. You don't have to buy any hokey brain-enhancing products or supplements off the Internet. Just get involved in many fun activities that enhance attention and self-control. Make sure that daily reading, music and other Brain Pyramid activities vastly exceed daily video game time.

*Dr. Donald Gilbert, MD MS, is associate professor of Pediatrics and Neurology, Cincinnati Children's Hospital Medical Center, and director of the Tourette Syndrome and Movement Disorders Clinics and Transcranial Magnetic Stimulation Laboratory.*

# Expanded rights for disabled in the works

By Gary J. Pandora

Most people with Tourette Syndrome are highly functional and remain gainfully employed. However, many must cope in the workplace with varying tic disorders. The level of disruption caused by the tic often determines whether a tic disorder will interfere with the ability to perform one's job.

This article is intended to provide some insight into the requirements imposed by Social Security for those seeking disability benefits with tic disorders. Also, this article will discuss the recently passed House Bill 3195, which, if approved by the Senate and signed into law, would significantly undo some of the U.S. Supreme Court's restrictions imposed under cases previously interpreting the Americans with Disabilities Act.

## Tic disorders

First, for people with tic disorders, Social Security offers two definitions of disability. The first tic disorder definition is found in regulations governing children's disabilities. Children claiming Social Security disability benefits due to tic disorders are required to establish:

-- Persistent and recurrent involuntary, repetitive, rapid, purposeless motor movements affecting multiple muscle groups with multiple vocal tics, OR

— Persistent non-organic disturbances of either vision, speech, hearing, use of a limb or coordination disturbances.

The level of severity required is a "marked" impairment in age-appropriate functions for at least two of the following:

1) cognitive or communicative functions; 2) social functioning; 3) personal functioning; or 4) difficulties with concentration, persistence or pace.

For adults with tic disorders the regulations are lumped together under the general requirements for somatoform (non-organic) disorders. These include conditions with no organic or physiological findings or mechanisms.

For adults there must be a history of multiple physical symptoms of several years duration beginning before age 30 that have caused the individual to take medicine frequently, see a physician often, and alter life patterns significantly. In the alternative, there must be persistent non-organic disturbances of either vision, speech, hearing, uses of limb, coordination disturbance (movement and its control) or diminished or heightened sensation.

Each of these limitations must lead to two marked restrictions of 1) daily living; 2) social functioning; 3) concentration, persistence or pace; or 4) repeated episodes of decompensation, each of extended duration.

Children or adults with tic disorders to the level of severity as described above might qualify for disability benefits.

## Americans with Disabilities Act may be revised:

On June 25 the U.S. House, on a vote of 402-17, passed H.B. 3195 with what some observers have called stunning speed. The bill would broaden the definition of disability under the Americans with Disabilities Act and would effectively



## A Legal View



reverse U.S. Supreme Court decisions on the rights of disabled employees in the workplace.

Key provisions of the bill are revisions to the term "disability" as used in the act. Disability would now encompass a broader range of physical and mental impairments.

Lawyers whose practices include employment disability discrimination as well as disability rights advocates have held the belief that U.S. Supreme Court decisions in 1999 and 2001 so curtailed the scope of disabilities protected under the act that claims made under A.D.A. were extremely limited. Under H.B. 3195, claims would be significantly broadened. Four key provisions to the bill are that it would:

-- Rebuke the Supreme Court's reasoning in key cases and direct the courts to broaden employee protection;  
-- Require courts to assess disability without regard to medications or assistive devices, such as prostheses, canes and crutches;

-- Require courts to evaluate permanent medical conditions with episodic effects, such as epilepsy and multiple sclerosis, even though the condition might be in remission when the employer takes adverse action; and

-- Order courts to reject a demanding standard for assessing

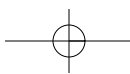
whether or not the condition substantially impacts the employee's daily life activities.

Some practitioners believe that under the new law, trial courts will need to give greater deference to evidence of disability and discrimination as now defined in the revised act.

H.B. 3195 received support from the U.S. Chamber of Commerce as well as various disability and civil rights groups. If approved by the Senate it would be submitted to the president ... stay tuned.

[Information used in this article was derived in part from: Bureau of National Affairs Inc. Employment Discrimination Report, July 2, 2008, and the Dow Jones Newswire. Also, special thanks to attorney Michael G. Moore, Tucson, Ariz., for his insights into ADA claims.]

*Gary J. Pandora is a former assistant attorney general for the state of Ohio. He has been in private practice in Columbus for more than 25 years. His practice involves personal injury, medical malpractice, Social Security and SSI disability claims. He can be reached at [gpandora@chorgood.com](mailto:gpandora@chorgood.com).*



# TSA Ohio Adventure Weekend 2008

Adventure Weekend 2008 at YMCA's Camp Willson was yet another tremendous success, as the photos of these happy participants attest. We had dozens of new youngsters and plenty of "old-timers" as well, who engaged in a wide variety of activities together. The isolation of having TS is one of the most frustrating things about it, so an event like this one is an especially sweet opportunity to get together and enjoy other people just like us.

To see dozens (and dozens!) more photos, go online to [www.tsaohio.org](http://www.tsaohio.org), or go to <http://tinyurl.com/5ccu4j>. Many thanks to Nelson Freed for taking and sharing the photos, and to Dick Bringardner, Fred Mooney, and all the other volunteers and contributors who made this such a success in helping these young people!

