



The Tourette Gazette – May 2008

Mark Your Calendars!

- TSA Awareness Month is May 15-June 15! [Learn more.](#)
- Sunday, May 18 – Train the Trainer Session. Learn how to give a presentation about TS to teachers and school staff. To be held at the Maryland Association of Nonprofits from 11:00am to 2:00pm. [Click here for more details.](#)
- June 14 – Tidewater Tourette Syndrome Support Group Bowlathon, from 12 to 4pm. Check the TSAGW website for details on this event and on the Support Group's schedule (www.tsagw.org)
- June 29-July 4 – Camp Connect, Buckeystown, Md. [Click here for details.](#)
- August 17, 2008 – Chapter Meeting featuring renowned TS researcher and pediatric neurologist Dr. Harvey Singer will be held from 1:00 to 3:00pm in the Weinberg Dublin Room at Mercy Medical Center. [Click here for details.](#)

Save these Dates

- November 14-15, 2008 – Special Education Law and Advocacy Boot Camp, featuring speakers Pete and Pam Wright. To be held in Columbia, Md.
- March 19, 2009 – Special Education Law and Advocacy Training sponsored by The Parents Place of Maryland, featuring speaker Pete Wright. To be held in Columbia, Md.
- March 5-8, 2009 – Council of Parent Attorneys and Advocates (COPAA) Annual Conference. To be held in Washington, D.C.

Also In This Issue

- [TS Awareness Month: May 15-June 15](#)
- [Train the Trainer Session: May 18](#)
- [Camp Connect – For Children and Teens with Tourette Syndrome](#)
- [Help a Kid Connect at Camp](#)
- [Ask the Expert: Dr. Barbara Coffey](#)
- [For Adults with TS: Survey to Capture Data on Living with Tics](#)
- [TSA Applauds the Passage of Genetic Information Nondiscrimination Act](#)
- [TSA Launches “Bridging the Gaps 2008”](#)
- [Free Resources for Young Children](#)
- [Tips from a Notable Employment Resource Each Tuesday!](#)
- [It's OK to Have TS](#)
- [Link of the Month: Step-by-step IEP Guidelines](#)
- [Attention Virginia Parents: It's Time to Take Action Now!](#)
- [A Big Thank You!](#)
- [Pat Eagen Receives 2007 Distinguished Volunteer Award at TSA National Conference](#)

TS Awareness Month: May 15-June 15

What is Your TS Advocacy IQ?

May 15 to June 15 is Tourette Syndrome Awareness Month. . . an opportunity for all of us to become better TS advocates and to help raise public understanding of Tourette Syndrome. Of course, it can be hard to raise TS awareness in those around you if you are still struggling with issues related to TS in your own life.

So, the first step is to ask yourself a few questions related to your TS Advocacy IQ. Are you comfortable speaking to others about your own TS symptoms or those of your child? If you are the parent of a school-age child with TS, have you worked with the school to ensure any necessary accommodations or support services are provided? Is your child or teen with TS able to explain their tic symptoms to peers or adults? Answering “no” to any of these questions may indicate a need for building advocacy skills within your family.

These skills do not develop overnight, however. Fostering the development of self-advocacy skills in children and teens, as well as educational advocacy skills among parents is at the core of the TSAGW mission.

Some skill-building options available to you through TSAGW include:

- Attend the Train the Trainer Session May 18.
- Explore how our services can help you expand your advocacy IQ.
- Contact us to schedule an appointment so you can peruse our lending library.
- Check out our many presentations designed to help you speak about TS to a variety of audiences.

[Back to Top](#)

Train the Trainer Session

Sunday, May 18, 2008; 11:00am to 2:00pm
The Maryland Association of Nonprofits
8720 Georgia Ave, Suite 303, Silver Spring, Md.

Learn how to give a presentation about TS to teachers and school staff. This informative presentation will guide you in helping school personnel understand some challenges faced by people with TS, Obsessive Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD), and learning disabilities. It is also ideal for newly diagnosed families who want to learn more about TS.

May is the ideal time to gain the skills you need for a presentation this coming fall! Please RSVP if you plan to attend: (301) 681-4133.

Attention Parents of High School Students!

If your student will take the SAT during the 2008/2009 school year, you should contact the school's counselor **now** to request accommodations for the test. Requesting 50% more time on the SAT requires up-to-date paperwork, including: current IEP, 504, neuropsychological or education testing results. Talk with your school's counselor regarding specifics. . . **but remember the deadline is NOW!**

DIRECTIONS from I-95: Take I-495 West (Capital Beltway) to Exit 30B - Colesville Road (Route 29). Follow Colesville Rd. to downtown Silver Spring, cross Georgia Ave. make a right onto Second Ave. and then make a right onto Cameron St. Park on Cameron St. or public lot on left side of the street.

From I-270: Take I-495 East (Capital Beltway) to Exit 31B - Georgia Avenue South. Follow Georgia Ave. south 1 mile to Cameron St. Make a right turn and park on the street or in the public lot on Cameron St.

METRO: Take Red Line to Silver Spring and exit Colesville Road. Walk two blocks north to Georgia Ave. Building is on the left.

MARC: Take the Brunswick line to Silver Spring. Walk two blocks north to Georgia Ave. Building is on the left.

PARKING - Use the public garage on Cameron St. between Second Ave. and Georgia Ave. Try to stay on the Georgia Ave. side of the garage. When you park, remember your parking space number. Take the elevator or stairs to Level 1 (Street Level). At the kiosk, pay for your parking in advance: \$0.60 per hour for the first three hours / \$0.40 per hour for each additional hour. Cash only, credit cards not accepted. We recommend paying for four hours (if attending a three-hour program). Turn left on Cameron St. Walk to Georgia Ave. Turn left on Georgia Ave. We are in the Metropolitan Building, Suite 303. For additional parking, there is also a nearby public garage at Cameron and Fenton St.

[Back to Top](#)

Are You Aware of the Services TSAGW Offers?

TSAGW is dedicated to serving the needs of families and individuals dealing with Tourette Syndrome, and the professionals who serve them. . .

We do this by providing a variety of services including:

- **Information Line** – Volunteers engage in one-on-one conversations that can help to draw out issues, guide in the avenue of treatment, direct a member to the appropriate services, as well as share compassion and understanding.
- **Resource Library** – A lending library of books, videos, and audiotapes are available for use by all TSAGW members. Available by appointment only.
- **Presentations** – Given by volunteers to a variety of audiences (including students and school staff upon request by a school or parent), presentations share information about symptoms of TS and associated disorders as well as possible accommodations and modifications.
- **Referrals** – Lists of area physicians, lawyers, educational advocates, school sponsored parent training centers, and organizations that teach social skills.

If you would like more information on the services we provide, please call the TSAGW office at 301-681-4133 or toll free at 877-295-2148.

Chapter Meeting to Feature Appearance by Dr. Harvey Singer

On August 17, the TSAGW Chapter Meeting will be held featuring an appearance by renowned researcher and pediatric neurologist Dr. Harvey Singer. Dr. Singer has been an active member of both the national Tourette Syndrome Association and TSAGW, serving on their respective boards and committees. The Chapter Meeting will be held from 1:00 to 3:00pm in the Weinberg Dublin Room at Mercy Medical Center (which accommodates up to 30 people.)

Mercy Medical Center is located at 301 St. Paul Place, Baltimore, Md.

[Back to Top](#)



Are You Off to College in the Fall?

If you will be away at college in the fall and want to request a single room (without a roommate) due to tics or other special needs, you must speak to the college's Disability Support Services office and to its Housing office immediately.

The Disability Support Services office may be called by many different names: Accessibility Services, Office of Accessibility, or Students with Disability Resource Center. Regardless of its title, as soon as you have been accepted and decided where you will attend, take the initiative to contact the school and to process your request. In order to receive accommodations, the student (not the parents) must register and provide documentation of a disability to the appropriate college office. Each school has different documentation requirements, so check with your college now to learn what they want you to submit.

To note: college transcripts do not show that a student received accommodations.

If you need more information on TS or on the services provided by TSAGW, go to www.tsagw.org or please call the TSAGW office at 301-681-4133 or toll free at 877-295-2148.



Camp Connect: For Children and Teens with Tourette Syndrome

Children's National Medical Center in collaboration with The Tourette Syndrome Association of Greater Washington will hold its annual sleep-over camp in Buckeystown, Md., from June 29-July 4, 2008.

Camp Connect provides an opportunity for children to build self-esteem, gain independence, and establish social connections with other children and staff who live with the condition.

Campers (ages 7-16) will participate in many activities, including team sports, hiking, canoeing, swimming, yoga and drama. Support groups and educational programs that promote knowledge, skill development and social connections are also available. At Camp Connect, children and teens gain better understanding of their condition, strengths and self-worth.

Camp Connect's staff includes a pediatric neurologist, social worker, physical therapist, nurse, and psychologist from Children's National Medical Center, in addition to trained counselors. Many counselors are college students and professionals with Tourette Syndrome. Campers benefit from their experience, knowledge, and understanding.

For \$650 per camper, children enjoy six days and five nights at a sleep-over camp filled with adventure, laughter, and friendships. The residential dorm offers comfortable beds, rooms, and showers. Payment plans, partial scholarships and a limited number of full scholarships are available to eligible campers. Camp Connect will try to accommodate any child with Tourette Syndrome who wants to attend.



To download forms and permission slips, go to www.tsagw.org

For more information contact:
Sandra Cushner-Weinstein, PT, LCSW-C,
Director, Children's Camps
The Dept. of Neurology
Children's National Medical Center
202-476-5142

[Back to Top](#)

Help a Kid Connect at Camp!

Some children in our community would love to attend Camp Connect this year but won't be able to because of financial constraints. Please help us send these children to camp by making a donation to TSAGW.

Most of us will receive our economic stimulus payments soon. What a great way to spend it, by helping a child go to camp!

Camp Connect is a wonderful opportunity for children with TS to feel accepted and included as part of a group—sometimes for the first time in their lives. Each year, campers arrive shy and afraid to leave their parents, only to be transformed by week's end, reluctant to leave their new friends behind. Many times, campers return as teen Counselors in Training (CIT) and then later as Counselors who encourage and support younger campers.

To sponsor a camper, you can mail a check to:

TSAGW

33 University Blvd. East

Silver Spring, Md. 20901

Please note on your check that the donation is for camp scholarships.

You may also donate online by going to: www.TSAGW.org and using the **Click and Pledge** link. In the comments section on the Pledge page, please denote that your gift is to support camp scholarships.

Join TSAGW!

Your annual membership helps fund all chapter services and programs such as: Telephone Helpline; Book and Video Lending Library; School Presentations; Professional Referrals; Buddy System; Chapter Meetings; Newsletters; Support Groups; and Chapter Member Directory.

Membership fees start at only \$45 per year!

To download, print, and mail your membership form, go to:

<http://www.tsagw.org/downloads/membershipform.rtf>

Give to TSAGW

Whether you would like to donate to TSAGW and support our efforts to provide much-needed services to TS patients, their families, and their surrounding communities. . . or you would like to give of your time and your talents. . . We would be grateful to have you give in any way that you can. . .

To learn about all of the ways you can donate, go to:

<http://www.tsagw.org/donate.html>

To learn of the many volunteer opportunities, please call the TSAGW office at 301-681-4133 or toll free at 877-295-2148.

The following article is reprinted with permission by the New York City Chapter of the Tourette Syndrome Association. It appeared in the Spring 2008 Newsletter.

Ask the Expert: Dr. Barbara Coffey

Barbara Coffey, M.D., M.S., is an internationally known specialist in Tourette Disorder and tic disorders who also has expertise in treating ADHD and OCD. She has been on the medical advisory board of the Tourette Syndrome Association and is on the advisory board of the New York City Chapter. She is the Director of the Institute for Tourette and Tic Disorders and Associate Professor of Child and Adolescent Psychiatry at the NYU Child Study Center.

Q. My 8 year old son has been diagnosed with Tourette's Disorder and Attention Deficit Hyperactivity Disorder (ADHD). His second grade teacher is concerned that he is unable to sit still in class, is frequently distractible and inattentive, calls out answers before questions are completed, and has difficulty completing his homework assignments. His tics are rather mild. Our pediatrician would like to prescribe medication to help our son, but he is reluctant to do so, since he is concerned that stimulants will increase our son's tics. What treatment options are available to help him?

A. This is a very common question from parents of children with ADHD and tics. There is a bidirectional overlap between ADHD and tics; that is, children with ADHD are at higher risk of developing tic disorders (10-30%) than children without ADHD (5%). In addition, children and adolescents with Tourette's Disorder referred for clinical evaluation are very likely to also meet criteria for ADHD (perhaps 50%). Thus, the two conditions often co-occur; the first step is to comprehensively evaluate the child and to try to determine which condition is associated with the most impairment or distress.

In children with comorbid (co-occurring) ADHD and tics, as in the 8 year old described, it is usually the ADHD symptoms (fidgetiness, distractibility, impulsivity and organizational problems) that cause the most clinical concern. Thus, treatment should be targeted to address the ADHD symptoms, and ideally, should not increase the tics. Treatments of ADHD include medication, behavioral, and educational interventions. Optimal treatment is multi-modal, which means drawing simultaneously upon several different modalities including medical, behavioral and educational components.

From the medical perspective, the most studied and generally most effective medications for ADHD are the stimulants, such as methylphenidate and dextroamphetamine. The first study of stimulants was in 1937, and there have been literally thousands of children and hundreds of adolescence and adults studied since then. The stimulants have been found in randomized, controlled clinical trials to be more effective than placebo for ADHD symptoms in about 80% of subjects. More recent studies have included adults and preschool children. They are generally well tolerated; most adverse effects are mild, such as difficulty falling asleep and reduction of appetite, and can be managed by adjusting the dosage and/or switching agents. The past decade has brought an improvement in stimulant delivery systems such as longer acting agents (Concerta, Metadate, Ritalin LA, Focalin XR and Adderall XR) which can be administered just once daily, and a transdermal (skin) patch (Daytrana) which is changed daily.

Early studies in the 1980s suggested that stimulants could induce or increase tics in patients with tic disorders or in those who are vulnerable to tic disorders, such as those with a family history of tics. As a result, many physicians and parents have been reluctant to prescribe stimulants to children with tic disorders and Tourette's. However, these early studies were confounded by the fact that most children with ADHD who are going to develop tic disorders or Tourette's are first brought in for evaluation at the time when the tics would be most likely to develop, at around age 7 or so. Thus, when a stimulant is prescribed and tics occur, it is most likely a temporal coincidence, and not a true causal association.

Fortunately, more recent studies, starting with the work of Drs. Kenneth Gadow and Jeffrey Sverd in the early 1990s, evaluating different doses of immediate release methylphenidate (Ritalin) on children's ADHD and tic symptoms, indicated that most children experienced a significant improvement in ADHD symptoms with little to minimal increase in tics. A large multi-center placebo controlled study of methylphenidate and clonidine individually and in combination, published by the Tourette Syndrome Study Group in February 2002, found that methylphenidate did not increase tics at a higher rate than placebo.

Of course, some children are sensitive to stimulants and may experience at least a transient increase in tics when a stimulant is started; usually the increase occurs at the beginning of treatment or during dosage titration. Usually the best approach is for physicians and parents to “wait it out” for several days, and most often the tics will return to their previous level. The stimulant can usually be adjusted to find the optimal dose that reduces ADHD symptoms but does not increase tics significantly.

If the tics do not reduce to a manageable level on the stimulant, either clonidine (Catapres) or guanfacine (Tenex) can be added in low doses. Clonidine and guanfacine, known as alpha adrenergic agonists, are anti-hypertensive medications that are commonly used off label as first line treatments for Tourette’s Disorder, as they reduce both motor and vocal tics. These agents have also been studied in the treatment of ADHD alone, since these medications reduce motoric hyperactivity, impulsivity and hyperarousal. Clonidine and guanfacine are not particularly helpful for the inattention and distractibility symptoms.

Another medication that has been studied in children with ADHD and chronic tics is atomoxetine (Strattera). This is a non-stimulant selective norepinephrine reuptake inhibitor that is labeled for treatment of ADHD in youth and adults. Strattera is generally well tolerated; adverse effects included reduced appetite, headaches, and nausea. Other medications that have been used off label to treat ADHD in children include modafinil (Provigil), a medication that is indicated for the treatment of narcolepsy in adults, and bupropion (Wellbutrin), an antidepressant medication.

It is important to remember that behavioral treatments are also effective in the management of children with ADHD. Treatment manuals have been developed by experts such as Dr. Russell Barkley that include careful attention to behavior in public settings, home token economy reward systems, and use of time outs. These techniques can also be used in school. In addition, educational intervention may include accommodations in the classroom such as preferential seating, frequent breaks, modification of homework assignments, and untimed testing. Full individualized educational plans (IEPs) may also be needed to address academic problems, including use of a resource room, aides in the class room, or substantially separate classrooms.

[Back to Top](#)

For Adults with TS: Survey to Capture Data on Impact of Living with Tics

Dr. Douglas Woods and colleagues from the University of Wisconsin – Milwaukee, along with several members from the national TSA Medical Advisory Board, have embarked on an important and extensive data collecting project designed to gather information about the impact of tics on the lives of adults with Tourette Syndrome and Chronic Tic Disorders. Sufficient data collection will allow TSA and the treating community to learn much more about a very broad range of issues relevant to having and coping with TS. Undoubtedly, this information will help better serve the TS community’s needs.

Internet-based, the survey responses will be submitted anonymously and strict confidentiality is assured. The survey is online. Only adults (over 18) who reside in the United States are eligible to participate. Completing the survey should take about an hour. If you would like to participate, please fill out the survey connected to this link:

https://www.surveymonkey.com/s.aspx?sm=X_2bx_2b8RocCCBAKzsphe791g_3d_3d

A link to the survey will also be placed on the TSA's website (www.tsa-usa.org) for your convenience. Additional information about this research and informed consent can be obtained via these links.

[Back to Top](#)

The following press release was distributed recently by the national Tourette Syndrome Association.

Tourette Syndrome Association Applauds the Passage of Genetic Information Nondiscrimination Act

Long-Awaited Legislation Will Protect Against Healthcare and Employment Discrimination

The national Tourette Syndrome Association, Inc. (TSA), hailed a vote on April 24, 2008 in the United States Senate approving comprehensive legislation, the Genetic Information Nondiscrimination Act (GINA), to ban genetic discrimination in health insurance and employment. The House of Representatives passed GINA in April 2007.

“TSA has worked alongside of the Genetic Alliance to call upon the Senate to support the procedural motions necessary to ensure the passage of this bill and today, we are very pleased with the passage of GINA in both the Senate and the House,” said Judit Ungar, President of the Association. “For the past two decades TSA has been adamant in our support of patient rights and protection. The American people cannot afford to wait any longer for protection against genetic discrimination,” she continued.

GINA (S. 358), would make it illegal for health insurers to raise premiums or deny coverage based on genetic information, and would prohibit employers from using such information for decisions on hiring, firing, promotions or job assignments. Genetic information, for the law's purposes, would include not only tests that determine variations in a person's DNA, but also a family history of a particular disease. But GINA does not prohibit discrimination once someone already has a disease, and some experts said such protection would have to be the next step. Passage of this initiative is crucial to ensuring the future of genetic research and the ability of all Americans to take advantage of genetic tests without fear that the information obtained will be used against them.

“We attribute this historic victory to the bipartisan support for the bill. With each passing day, Congressional co-sponsors were being added to GINA, resulting with a record high roster of Congressional supporters, and we know it is due in part to TSA's Trips to the Hill, letters of support, and calls for action for GINA that have made such a difference.

There is truly power in numbers,” said Ms. Ungar. TSA wishes to thank Congress for working to provide fundamental protections against the misuse of genetic information especially in health insurance coverage and employment situations. Especially, TSA acknowledges the sponsors of the bill, Rep. Louise Slaughter (D-NY) and Rep. Judy Biggert (R, IL), Senators Olympia Snowe (R-ME), and Edward Kennedy, chairman of the Senate Health Committee, for their leadership and efforts on this long standing and critical issue of importance. In addition, TSA expresses its gratitude to Senator Tom Coburn (R-OK) for his views and support of GINA.

[Back to Top](#)

TSA Launches “Bridging the Gaps in 2008”

With the passage of the GINA, the national TSA is unveiling “Bridging the Gaps,” a public awareness advocacy campaign. The need to address the lack of confirmed diagnoses of TS in medically underserved areas is still a critical issue. Realizing the goal of bridging these gaps among the minority and underserved communities, TSA is pushing for deeper awareness of TS.

TSA is asking its chapters and support groups to help raise awareness about TS in their local communities through meetings and discussions with local elected officials, members of Congress, and community leaders. **TS Government Relations Awareness Week (May 26-June 2)** is designed to raise local, state, and federal elected officials' awareness of issues impacting families living with Tourette Syndrome.

You can influence change in your community during TS Government Relations Awareness Week—and all year long—by joining TSA’s efforts to hold meetings with community leaders and elected officials. TSA has developed a host of materials and guidelines to help you get involved and be an effective advocate for change.

To participate in the “Government Relations Awareness Program,” please contact Elridge Proctor at TSA: elridge.proctor@tsa-usa.org.

[Back to Top](#)

Who Says ‘Nothing in Life is Free’?!

The website Counselingstore.com has a free resources page designed especially for young children. Every month, in their newsletter they share a list of favorite websites and free resources for parents, teachers and counselors.

Some of their most popular downloads and resources include:

- Wild Animal Feelings Poster
- It's Fun to Be Good Coloring Book
- The Cooperation Maze
- Good Values Word Search
- Stress Scale Bookmark
- Feelings Flash Cards
- Positive Feelings Skee Ball
- My Personal Museum

- Good Behavior Road Signs

You can access all of them by going to: <http://resources4kids.com/freeresources2.html>

Tips from a Notable Employment Resource Each Tuesday!

Joyce Bender, CEO & President of Bender Consulting Services, was the keynote speaker at the World Congress Expo on Disabilities in November, 2007. She survived a life-threatening accident caused by a misdiagnosis of epilepsy. Due to her personal living experience with both epilepsy and a hearing disability, she founded Bender Consulting Services, Inc., which has grown into a highly regarded employment resource.

To check out their website, go to: <http://www.benderconsult.com/index2.html>

Joyce Bender also hosts a radio show "Disability Matters with Joyce Bender" on www.voice.voiceamerica.com every Tuesday from 2:00-3:00pm Eastern Time. The toll-free caller/listener number is 1-866-472-5788.

[Back to Top](#)

The following is a reprint of an article that appeared recently in MIX, a multicultural magazine for Hampton Roads, Va.

It's OK to Have TS

By Lakeshia Artis

Stephen McCall looks and acts normal. He speaks eloquently and has a charming personality. But he has spent a lifetime keeping a secret, a condition that makes him appear different.

Since the age of 10, McCall has been diagnosed with Tourette Syndrome, a neurological disorder. He twitches uncontrollably.

It's a secret McCall waited almost seven years to tell his good friend James Johnson about.

Looking back over the years, Johnson said he doesn't recall seeing anything strange except for a nervous twitch of the mouth or blinking of the eyes.

"I was very surprised," Johnson said. "When you think of Tourette's, you think of a person who is slightly incapacitated and not able to carry out the full functions of a normal person."

Believing he would be shunned like an outcast, McCall decided to keep the disorder a secret by temporarily suppressing the tics.

"I thought people would ostracize me from society," said McCall who lives in Isle of Wight.

Tourette's symptoms are tics of the face, arms, limbs that are frequent, repetitive and rapid. One of the earlier signs of Tourette's is a facial tic that causes eye blinking, nose twitching and grimacing.

According to The National Institute of Neurological Disorders and Strokes, it affects people from all ethnic groups; males are affected about three to four times more often than females. An estimated 200,000 Americans have the most severe form of TS, and as many as one in 100 exhibit milder and less complex symptoms such as chronic motor or vocal tics or transient tics of childhood.

From the age of 15, McCall was determined not to let the condition overcome him. He stopped taking his medication because of the side effects and learned how to temporarily suppress the involuntary movements and vocalizations caused by the disorder.

“I was a zombie,” McCall said of the medication effects. “When I came home I slept, when I went to school I slept.”

This resulted in less than stellar grades in high school. People began to tell him he wouldn't amount to much. Proving them wrong, McCall is now a successful GS-12 deputy branch chief of the Space Systems Branch of Directorate of Requirements and Air Combat Command program manager for a \$13.4 billion communications program at Langley AFB.

Until recently, most of his family, friends and co-workers were also unaware that he had Tourette's.

“I would tell people I had allergies,” he said to explain a tic or rapid blinking. “When you suppress the tics in public, it makes you uncomfortable. It's like a sneeze. If you try to hold it in, it eventually comes out.”

In most cases, if he feels an episode coming on, he may go to the bathroom.

“I felt bad for him because I had seen so many stories on TV where people with TS didn't have friends and no one understood them,” said his mother, Marilyn McCall, of when a doctor diagnosed his condition. “I was afraid he would grow up lonely.”

Marilyn McCall says his father had a hard time coping with their son's condition.

“He didn't want to admit something was wrong with him, and he wanted everything in his life to be perfect,” Marilyn said.

On the other hand, she was never embarrassed nor shied away from her son's challenge. After finding out about McCall's TS, Johnson's opinion of his good friend never changed.

“Today, I look at all the things he has accomplished, having being around him myself,” Johnson said. “I thought it was remarkable. It's caused me to look up to him more than I did before.”

McCall credits his faith, will and determination for giving him the ability to be more open about Tourette's and to have a positive outlook.

“A lot of people don't know what Tourette's Syndrome is,” McCall said. “If you say the ‘cursing disease’, then their like ‘Oh’ because that's what the world portrays it to be,” he said.

Coprolalia, which is the uttering of obscenities and ethnic slurs, occurs in fewer than 15 percent of people with TS.

“It makes me want to kick myself when I hid it for so many years, because I could have been helping people a long time ago,” said McCall who wishes he had come forward about TS sooner. He’s making up for lost time.

While living in Florida, McCall founded a Tourette’s support group in Ft. Walton/Pensacola counties. Shortly after moving to Virginia, in 2007, he co-founded the Tidewater Region Tourette’s Syndrome support group. He’s also on the board of directors for the Tourette’s Syndrome Association of Greater Washington.

In hopes of helping children cope with the condition, McCall is working on a book about TS titled, “Tyrannosaurus Tic: A Boy’s Plight with Tourette’s Syndrome,” which is due out this fall from Trafford Publishing.

“I wanted to write a book basically dealing with the things I went through as a 10 year old,” McCall said. “It’s actually a funny book because it shows it though the perspective of a child.”

Susan Jacob, executive director of the Greater Washington chapter, credits McCall’s enthusiasm and willingness to get involved.

“I was impressed by his story,” said Tracy Flynn, a spokeswoman for The Tourette Syndrome Association in New York. “He wants to be a role mode to young people young and old with TS. You have to put a face on the disorder.”

McCall’s advice to parents of children with Tourette’s is simple – treat them as though they’re normal because they are. “Treat them exactly like you would treat them if they didn’t have TS,” he said. “Keep on encouraging them and make sure they know they can do anything in their life.”

The group meets regularly at the Virginia Beach Central Library, 4100 Virginia Beach Blvd. For more information on the Tidewater Support Group, call Stephen McCall at 292-9329 or Jessica Gibson at 713-4881.

Link of the Month

The Individuals with Disabilities Education Act (IDEA) addresses the regulations, allowances, and student rights regarding the creation and maintenance of Individualized Education Programs (IEPs) for children with disabilities, including preschool-aged children. This website provides an informative, well-written step-by-step guide for the IEP process (authored by the US Department of Education):

<http://www.ed.gov/parents/needs/speced/iepguide/index.html#process>

Although created in 2000, updates have been made as recently as 2007 (to address most major changes to IDEA in 2004.) It is important to note that each state writes their own specifics related to the regulations, which must meet or exceed those outlined by the federal government.

[Back to Top](#)

Attention Virginia Parents: It's Time to Take Action Now!

Does your child have an IEP or IFSP? Do you like having a voice at the table about your child's education?

Is your child receiving or has your child received special education services? Do you ever request an IEP meeting? Is it important to you to remain an equal member of the IEP team? Are IEP progress reports important to you? Or are you worried that your child may lose special education-related services?

The Virginia Board of Education (VBOE) is proposing a major change to Virginia's current special education regulations. The VBOE proposed draft is a rewrite of these current special education regulations and not simply a revision. If you wish to continue to have input that is heard and be a full and equal member at IEP meetings, you need to speak up now!

The bottom line is that parents and supporters must submit public comment or the Virginia Board of Education won't think the proposed regulations are of concern to Virginia's parents. If, however, the VBOE approves the proposed regulations as is, the entire special education process in Virginia will be permanently changed, with more decision-making going to the schools and LESS rights and protections for parents:

- Less involvement by parents in the referral process. There will be no STATE-required timelines, no required STATE procedures for involving parents.
- Less involvement by parents in the IEP.
- Less involvement by parents in monitoring progress (since IEP progress reports would not be required as often as currently).
- Less involvement by parents in termination decisions.

The voices of families, teachers, students, and others who care about children with disabilities need to be heard during the public comment process and at upcoming public hearings to ensure the draft regulations go back to the drawing board! Virginia needs to continue current protections and improve students' opportunities for long-term success.

What YOU can do to help...

1. Go to the following website: <http://capwiz.com/arcofva/state/main/?state=VA>. Click on the blue "TAKE ACTION" to submit a copy of The Arc of Virginia's suggested public comment. Feel free to edit, add to, or personalize these public comments as you wish.
2. SPEAK OUT at the Public Hearings on the Special Education Draft Regulations which will begin on May 12, 2008. These public hearings will be held regarding the Board of Education's proposed changes to Virginia's special education. When you attend, bring a copy of the public comments and say a few words about how YOU or YOUR child would be impacted by these changes. To view The Arc of Virginia's public comment, visit www.arcofva.org.

For your area's location and date please visit <http://www.arcofva.org/Flyer-SpecEdPublicHearings.pdf>

The Arc is also hosting a series of meetings to help prepare parents and advocates to speak at the Public Hearings. These workshops will be held in May. To register or for more information, contact The Arc of Northern Virginia at 703-532-3214, Ext.115, or email: tmarsili@thearcofnova.org or sktripp@thearcofnova.org.

Tourette Syndrome Genetics Study

What is the Study About?

Research is being conducted to find the genes that are important in the development of Tourette Syndrome. This study, sponsored by the Tourette Syndrome Association, will provide researchers with advanced information about Tourette Syndrome and its relation to human genetics.

What Will Participation Involve?

Participating in the TS Genetics study will involve one visit to Johns Hopkins Hospital. Families — including the affected individual — will be asked to complete some self-report questionnaires and give a small amount of blood. Visits typically last 1-2 hours or up to three hours if the parents participate. If your family is unable to travel to the hospital, special arrangements can be made for the researchers to travel to a more convenient location.

Who is Eligible to Participate?

Individuals (child or adult) diagnosed with TS. Parents of the person with TS are also eligible to participate.

All children/adults with TS have to be available for a blood draw and interview; if biological parents are available they can also participate in a blood draw and interview.

Contact Information

Marco Grados, M.D., M.P.H.; Phone number: 443-287-2292; email: mjgrados@jhmi.edu

[Back to Top](#)

A Big Thank You!

Dedicated, knowledgeable volunteers are critical to TSAGW's success! We recognize and thank these generous supporters! Your skills and time are valued and appreciated.

Acknowledgement of Major Gifts

Platinum Circle Donors

TSAGW deeply appreciates the extraordinary generosity of the **Ochsman Foundation's** commitment of an annual donation.

Platinum Circle Donor Members have given a generous gift of \$5000 – \$10,000 to TSAGW.

Silver Circle Donors

TSAGW deeply appreciates the extraordinary generosity of **Bebe Edmondson** and **Jose Chieng**.

Silver Circle Donor Members have given a generous gift of \$500 – \$2000 to TSAGW.

TSAGW thanks all donors, including those not recognized by name.

At least half of our Year-End contributions come from people electing to donate anonymously. We value each donation and truly appreciate your support and generosity.

In Honor Of . . .

Bebe Edmondson and **Jose Chieng** express their appreciation of **Susie Edelson's** commitment and work for TSAGW with a generous donation "In honor of Susie Edelson."

Please note, for legal reasons, all donations are considered anonymous contributions. We are allowed to acknowledge only those donors who place a check in the acknowledgment box.

This Newsletter is a publication of the Tourette Syndrome Association of Greater Washington which is solely responsible for its contents, unless otherwise indicated. National TSA has not reviewed the content of this newsletter.

Our Thanks to . . .

Services

Gary Bergman, Chair, Services Committee

NBC 4 Health Fair

Gary Bergman
Dara Deutsch
Susie Edelson
David Ginsburgh
Cathy Kramer

National Conference

Gary Bergman
David Ginsburgh
George Grinberg-Funes
Abdella Kershi
Hope Wyatt

Annual Meeting

Gary & Linda Bergman – Food donation & preparation

Michele Cole, LCSW - Speaker

Dara Deutsch – Leader and Mentor

Khristopher Gibson – Youth Ambassador

Jessica & Danny Gibson – Training & support to Youth Ambassador

George Grinberg-Funes, Meeting Preparation

Dr. Bennett Lavenstein - Speaker

Steve McCall – Leader and Mentor

Eric Mumford – Leader and Mentor

Rabeka Rowland – Presentation Support for Youth Ambassador

INOVA Fairfax Hospital for donating the facilities; **Starbucks** for donating the coffee and supplies.

If you need more information on TS or on the services provided by TSAGW, go to www.tsagw.org or please call the TSAGW office at 301-681-4133 or toll free at 877-295-2148.

More Thanks to . . .

Referral List

Cathy Kramer

Support Group Leaders

Jessica Gibson

Stephen McCall

Health Fairs

Tracy Louis-Charles

Cathy Kramer

Jim Merklinger

In-Services

Sonny Bell

Pat Eagen

504/IEP Meetings

Susie Edelson

Executive and Administrative

Pat Eagen, Chair (Admin Committee)

Legal Counsel

Jim Merklinger

Board Counsel

Tiffany Payne

Information Technology Support

Sonny Bell

Chandra Chandrasekaran

Rick Edelson

Administrative Office Assistance

Ashley Grinberg

Matthew Grinberg

Newsletter

Todd Feldman, Contributor

David Ginsburgh, Editor

Kim Murphy, Editor

Website – about to be released!

Chandra Chandrasekaran

Marie Kaddell

Victor Lawrence

Stephen McCall

Kim Murphy

Fund Raising

Laura McGrew, Chair

Top Fundraiser

Hope Wyatt, 2007 Bowl-a-thon

Wine Gala

Karen Asman, Co-Chair

Susan Wyatt, Co-Chair

Susie Edelson

Laura McGrew

Jim Merklinger

Donna Osborn

Tiffany Payne

Laurie Wilner

Hope Wyatt

Starbucks Campaign

Laura McCafferty

Small Business Owners Special Sales Event

Melody Wright, proceeds to Camp Connect

[Back to Top](#)

Pat Eagen Receives 2007 Distinguished Volunteer Award at TSA National Conference

The following excerpt is from the speech given to during the award ceremony.

Pat has worked tirelessly on behalf of people with TS for over 35 years. Pat's decades of service to people with TS are laudable and illustrate the depth of her commitment. As a founding member of TSAGW, Pat provided the leadership,

energy and dedication to nurture this fledgling group into the well developed and mature organization we now know as the Greater Washington Chapter.



Rovena Schirling (right) presents 2007 Distinguished Volunteer Award to Patricia Eagen

Reviewing the history of TSAGW is an appropriate means to evaluate Pat's long and stellar service. In the mid 1970's, Anne Abramson, a local, caring TS family member, started contacting people to begin a group that would serve TS families. Pat got involved, and soon Pat was serving as President of the nascent Washington DC organization. Pat was advocating for children in schools, speaking at hospitals and at education symposiums, as well as helping medical professionals and families recognize the symptoms of TS.

As a registered nurse, Pat saw the need for identifying and cultivating relationships with medical professionals and providing knowledgeable referrals for families and individuals. She and a small cadre of steadfast volunteers provided information and services. They struggled with little funding, but were making a mark as a credible group providing valuable help to families and professionals. By 1980, TSA was impressed with Pat's infectious determination and her impressive results and asked Pat to serve on the Board of Directors. She enthusiastically volunteered yet again.

With clever coordination from TSA, in 1981, the popular television series "Quincy" and its star, Jack Klugman, provided the public awareness that was desperately needed. The March 4, 1981 show focused on TS. Following the show's credits, the NBC Baltimore affiliate posted Pat's home phone number as the local TS contact. The show aired from 10:00- 11:00 PM, and Pat's phone started ringing at 11:01. After this night, the chapter grew beyond Pat's kitchen table. Pat found a donor willing to provide a room, and Pat created a new home for the group and established culture of professionalism.

The Greater Washington Chapter was formally recognized with Chapter Charter signatures on November 4, 1982. Within four months, Pat had added 100 families to the local mailing list. TSAGW was now reaching a grand total of 1, 035 families. Under

Pat's leadership, TSAGW thrived, support groups continued to flourish, and Pat was managing a large group of volunteers. Eventually, Pat stepped down and pursued employment in a field not too far from TS: Attention Deficit Hyperactivity Disorder working with researchers at NIH.

The story doesn't end here, however, as Pat returned to TSAGW's Board in 2001. Over the last year alone, Pat has served as Acting Treasurer, Secretary, ED trainer and mentor, charity application expert, office administrator and file clerk. In addition, Pat continues to provide staff and peer presentations all over D.C. and the states of Maryland and Virginia. Clearly, TSAGW continues to heavily rely on Pat's willingness to guide and to serve.