



The PA Tourette Syndrome Alliance is a non-profit organization that promotes awareness and acceptance, provides education, and assists families, schools and communities while advocating for individuals with TS.

Brain Chemical Aids Tic Control in Tourette Syndrome, Say Researchers

01 Oct 2015
PA 153/15

A chemical in the brain could potentially be harnessed to help young people with Tourette Syndrome (TS) to overcome the physical and vocal tics associated with the neurological disorder, say researchers. In a paper published in the journal *Trends in Cognitive Sciences*, academics from The University of Nottingham reviewed recent evidence that the neurochemical known as Gamma Aminobutyric acid (GABA) is responsible for dampening down the hyperactivity that causes the repetitive and involuntary movements and noises.

They found that increases in the production of GABA as a result of changes in the brain during adolescence may contribute to an improvement in symptoms for the majority of people with TS and could offer a new avenue for treatments that lead to targeted increases of the chemical in the areas of the brain that control motor function.

Professor Stephen Jackson, in the University's School of Psychology, said: "This is potentially a very important finding. A widely held view has been that unwanted movements such as tics in Tourette syndrome are actively suppressed through the recruitment of frontal brain areas involved in volitional action and cognitive control. The finding that individuals with Tourette syndrome exhibit increased GABA in brain areas



linked to the planning and selection of movements offers a more parsimonious account for how tics might be controlled in Tourette syndrome. Namely that motor excitability is reduced locally within brain motor areas through the operation of GABA-mediated 'tonic inhibition.' This finding needs to be further replicated but if it proves to be a robust finding it may have important implications for therapies for neurodevelopmental disorders."

Uncontrollable tics

TS is a neurological disorder affecting around one per cent for all school-age children, who are affected by an evolving series of chronic physical and vocal tics which develop over time and become increasingly worse.

While children with TS can often suppress their tics, it takes great effort and can be both uncomfortable and stressful and eventually builds up until the urge to tic becomes uncontrollable. Tics are at their worst for people with TS aged between 11 and 14 years old, but for the majority begin to improve throughout adolescence and into early adulthood. For a substantial minority though (around 20 to 30 per cent) the tics continue and for

some become increasingly severe and resistant to treatment.

Previously some researchers have thought that the successful control of tics comes about over time through the

purposeful and continual effort to suppress them.

However, the Nottingham team — which also includes researchers from the Institute of Mental Health — believe it is more likely that tics improve as a result of the changes in brain structure and function that occur during adolescence. Specifically, they believe that this could largely be attributed to the neurochemical GABA — the primary inhibitory transmitter found in the central nervous system, which plays the principle role in controlling the 'excitability' of neurons. The brain's neural circuits are established early during development, with milestones including the creation and migration of neurons, the formation of synapses — the pathways by which the neurons carry their electrical signals — and the strengthening of those synaptic connections.

Self-regulating techniques

These early developments produce brain networks with a balance of influences that will excite and inhibit the brain and a disruption to this natural order has been associated with a number of common neurodevelopmental disorders including TS.

PA Tourette Syndrome Alliance, Inc.
P.O. Box 148
McSherrystown, PA 17344

Phone: 1-800-990-3300
or 717-337-1134
Fax: 717-698-1420

www.patsainc.org

STAFF

Administrator/Consultant:
Sherrie Sponseller

Assistant Administrator/Consultant:
Sabrina Bosse

Outreach & Volunteer Coordinator:
Sara Woolf



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Volunteer Programs:

We need you! Anyone can join our volunteer programs at any time. Recorded trainings are available for most positions and updates will be completed each summer. To start the process, just let us know what program you are interested in by emailing saraw@patsainc.org or by completing a volunteer application online.

- **Volunteer consultant** — trained volunteers who can assist with disability advocacy at school meetings.
- **Speaker's Bureau** — trained volunteers who can provide trainings for educators, peers and other community members.
- **Youth Advocate Program** — youth ages 12-25 who have trained and have materials to do an information board, bulletin board and give a basic training on TS.
- **Outreach/Information Program** — knowledgeable volunteers who "staff" an information booth at local events.

Volunteer Consultants



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Magnus Lewis
Westmoreland/Western PA
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Susanna Roode
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And other members not listed

Disclaimer

This newsletter is published two 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 Alliance (PA-TSA).

While we will attempt to respond to all mail, we are not able to answer medical questions.

The PA-TSA, Inc. does not endorse products, services, or manufacturers. Such names appear only as information for our members. PA-TSA assumes no liability whatsoever for information about 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 PA Tourette Syndrome Alliance.

2015 TS Family Camp Sponsors

Held the weekend of June 12-14, 2015!



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2015 TS Family Retreat Sponsors

Held the weekend of October 24-25, 2015!

Brad Cohen Tourette Foundation

Kenny's Dream Foundation

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Family Practice Center; Dr. Cox

Thank You for supporting our Camp Programs!

To support the 2016 Camp/Retreat or to donate scholarship funds, [Click Here](#)

PA-TSA Supporters: Important Request

As you probably know, the State of Pennsylvania is over 7 months into a budget stalemate, with no end in sight. Today the PA Tourette Syndrome Alliance is weathering the storm without our essential State grant of \$150,000 from the PA Department of Health. So far PA-TSA has not had to borrow money or cut services because of our ongoing fundraising efforts and by utilizing a modest reserve of \$75,000. However, that money will not last forever, and soon we will face tough decisions on what programs must be reduced or eliminated.

For 30 years, donors like you have supported our efforts to change the way people view this misunderstood neurological disorder, and we don't want to stop our momentum. Please help us sustain our programs by donating to our overall efforts or by choosing the one that means the most to you!

If you want PA-TSA to provide handouts and answer questions for families and teachers so that these individuals can better understand a child's tics and other symptoms, then consider giving to our **Information Program**. If you want to support having Educators, Professionals, and Peers trained so that they can better support, understand, and include children with TS, then give to our **Education/Training Program**. If you feel it's important that PA-TSA consultants be able to assist families with school and mental health meetings, and to help parents support their child's rights, then designate your donation to our **Disability Advocacy Program**. If you value PA-TSA's efforts to increase community awareness by producing videos, Public Service Announcements, and by direct mail to doctors' offices and schools, then give to our **Awareness Program**. If you want to help families receive support and training through our popular TS Family Camp and Family Retreat programs, then donate to our **TS Family Camp & Retreat**. And if you find **all** of these programs important, you can to make a donation to support our **"Overall Programs"**.

It is our hope that PA-TSA will not need to reduce or make changes to the services we provide as we move through these fiscally trying times, and your help can make that difference! So please consider making a donation of \$100 or more right now. This can be done through a one-time donation or as a monthly donation charged to a credit card. To donate online [click here](#). Whatever level of support you choose, please know that your donation is truly appreciated by those affected by Tourette syndrome in Pennsylvania.

**Will you consider doubling your impact by checking to see if your place of business provides matching funds for donations?

Please make your donation to:

PA-TSA, Inc. P.O. Box 148, McSherrystown, PA 17344

Donor Name: _____ Address: _____
 Email: _____

YES, I would like to help sustain PA-TSA by donating to the following programs:

Overall Support **Information** **Education/Training** **Disability Advocacy** **Awareness** **Camp/Retreat**
 \$25 \$50 \$100 \$200 \$500 \$1000 Other

My donation is enclosed **OR** Bill my credit card one time or monthly
 Visa Master Card Discover American Express

Credit card # _____ Exp. Date: _____ CVV#: _____

Cardholder signature: _____

All contributions are tax deductible in accordance with I.R.S Section 501 (c) (3). The official registration and financial information for PA-TSA, Inc. may be obtained from the PA Department of State by calling toll-free within PA 1-800-732-0999. Registration does not imply endorsement.

Give Support...Get Support

We have local support groups in several areas of the Commonwealth, along with an online support group that is available 24/7! If you are interested in starting a support group in your area or helping with an existing support group please contact our Outreach & Volunteer Coordinator – Sara Woolf at saraw@patsainc.org.

[Click Here for more information about our Support Groups!](#)

Youth Opportunity

Last summer, PA-TSA, developed a brand new opportunity for our Youth. Our first Youth Board Representative, Adam Fishbein, was appointed by the Board of Directors in September. The Youth Board Representative serves PA-TSA's younger membership by helping to guide the Board of Directors in understanding the needs and desires of our youth. This position, held by a youth member between the ages of 16-18, holds an annual term from June-June. Be on the look-out for more information on how to become involved as the next Youth Board Representative.

The application and information for next year's Representative will be released on April 1, 2016.

Donations In Loving Memory:

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What's this TS Camp all about?

The PA Tourette Syndrome Alliance has been hosting its Tourette Syndrome Family Camp for 10 years! This camp brings families from all over the state (and beyond) here to South Central PA for an unforgettable weekend. Children have the opportunity to meet other children and adults with Tourette syndrome and attend typical camp activities such as creek stomp, climbing wall and swimming. Parents have the opportunity to attend workshops and connect with other parents that are navigating a similar journey through TS. All this, while knowing their child/children are in an environment where they are understood. As one mother put it, "This is the only place I come and know that I can let my guard down." She explained, "I know I won't be judged as a parent, nor will my child be judged. I can sit and have a conversation while my children go off and play without worry that I will be approached about an 'issue' with my children. My entire family looks forward to camp all year long."

The 2016 Tourette Syndrome Family Camp is shaping up to be another spectacular event! We are expecting over 200 attendees and a crew of over 30 volunteers. Kids will get to choose from specialty activities like Water games, Wilderness Survival, Gone Fishing & Mad Scientist. We have a Young Motivational speaker for the children and a Tic Talk session for kids diagnosed with TS. We are even planning an activity exclusively for the siblings that join us! Our parents and adults will receive support in our formal discussion

groups, but they will also have time to relax and attend informational workshops on Sensory Sensitivity, Executive Dysfunction, and Taboo Topics, just to name a few.!

Camp will be held June 10-12, 2016.

Registration opens February 29th.

[Click here](#) for more information!

TS Family Camp through the years:



(cont from page 1) GABA is the main inhibitory neurotransmitter in the brain and contributes to almost all functions. Findings from previous research support the idea that TS is linked to changes in the levels and function of GABA in the brain. MRI studies have consistently shown a reduced level of GABA in the brains of those with TS and post-mortem studies have shown this decrease to be as much as 50 per cent.

GABA is believed to have an inhibitory function in the areas of the brain associated with higher motor function and that a decrease in this inhibiting factor leads to the tics experienced by people with TS.

A long-standing theory is that people with TS gain control over their tics by developing self-regulating techniques to compensate, which in turn lead to a physical 're-wiring' within the neural pathways of the brain.

The Nottingham experts however believe that this new control may come as a result of a higher amount of GABA, which is being released in the brain during adolescents, and which inhibits the motor regions such as the Supplementary Motor Area. The findings could offer a new avenue for treatments which mimic this inhibiting affect within the motor function areas of the brain and could potentially offer new hope for people with TS whose disorder stays with them into adulthood and has a devastating impact on their quality of life and their ability to make friends and maintain relationships.

The paper Inhibition, Disinhibition and the Control of Action in Tourette Syndrome, is published in the latest issue of Trends in Cognitive Science.

More information is available from Professor Stephen Jackson in the School of Psychology, University of Nottingham on +44 (0)115 846 6020, stephen.jackson@nottingham.ac.uk

2016 EVENTS!

Day at the Capital- May 3, 2016

Highmark Walk Pittsburgh- May 14, 2016

Highmark Walk Harrisburg- May 21, 2016

TS Family Camp- June 10-12, 2016

Run for Tourette— Oaks, PA- Oct. 2016

TS Family Retreat- Oct. 2016

To find out more information about upcoming events visit our website at www.patsainc.org and click on news & events



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