



# Connections

Newsletter of the Tourette Syndrome Association of Washington and Oregon, Inc.

## Marc Elliot will be Speaking in Tacoma!

On **April 28th**, at the **University of Washington – Tacoma's** Carwein Auditorium, at 12:30 pm and at 6:30 pm, hear inspirational speaker **Marc Elliot** share personal anecdotes about living with Tourette's Syndrome (TS).

Diagnosed with the disorder at age 9, Elliot has become widely known for his humor and powerful insights on the value of tolerance. This is a free event open to the public. The event is hosted by the University of Washington's Housing Services and Student Involvement.

Parking around the UW-Tacoma campus is limited. For questions about this event, contact: **sabdiv@uw.edu**.

## TSA Youth Ambassador Featured in The Oregonian

This year, the Washington and Oregon chapter selected **Jordan Britton**, age 15 from Oregon, to receive a Youth Ambassador Scholarship. This scholarship involves training in Washington, D.C. After receiving training, Youth Ambassadors apply the skills they learned to tell their story and educate policy makers about TS. For example, Jordan visited the offices of his Member of Congress and both U.S. Senators from Oregon at our nation's capitol. See article by Melissa Navas in *The Oregonian*.

This article may be found at the following web link: [http://www.oregonlive.com/beaverton/index.ssf/2010/04/beaverton\\_boy\\_with\\_tourettes\\_is\\_a\\_national\\_ambassador\\_to\\_help\\_others\\_understand\\_the\\_disorder.html](http://www.oregonlive.com/beaverton/index.ssf/2010/04/beaverton_boy_with_tourettes_is_a_national_ambassador_to_help_others_understand_the_disorder.html)

Learn more about Jordan, a very inspirational young man, in our next edition of *Connections*.

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## Update about the Local Chapter: Tourette Syndrome Association of Washington and Oregon, Inc. Signs Chapter Agreement with TSA National Association

In late March, the Board of Directors approved of adoption of a Chapter Agreement with the national Tourette Syndrome Association. Chapters must agree to the terms of a Chapter Agreement with the national association. While a formality, at one level, adoption of a chapter agreement is a substantive matter. The national association establishes standards that all chapters that are chartered by the national association must follow.

## NIH Research Study Needs Your Help!

The NIH recently awarded more than \$1.7 million to TSA to conduct a nationwide study aimed at finding genes for TS. This research study is being conducted by the TSAICG. TSAICG is working with leading scientists and physicians from around the world to find some of the genes that “cause” TS.

Thousands of people with TS and their families have already participated in TSAICG studies. As a result, several chromosomes have been identified that may contain TS genes. In order to pinpoint specific TS genes, researchers need even more volunteers.

Three thousand (3,000) more individuals diagnosed by a physician with Tourette’s Syndrome (TS) are needed for research.

The research has two key parts:

Part 1: A Web-Based Questionnaire about tics and related behaviors

Part 2: A donation of blood (Coordination of blood donations can be arranged by the research organization and your physician or Quest Diagnostics.)

Finally, a small number of individuals will be asked to take part in a longer interview. This can be completed by telephone. It should take one to two hours.

This is an important and exciting opportunity to advance research on the genetics of TS!

**If you or someone in Oregon or Washington would like to learn more about this research, please go to <https://findTSgenes.org> or telephone the West Coast Recruitment Center at 1-TS STUDY W 50 (1-877-833-9950).**

## NIH Brain Chemistry Study at Johns Hopkins Study

Johns Hopkins Hospital, a leader in medical research, continues to be looking for research subjects for its brain chemistry research regarding Tourette’s Syndrome (TS) and Obsessive Compulsive Disorder (OCD).

This research study is one of the largest NIH funded projects in brain chemistry imaging in the nation. The Principal Investigator, Dr. Dean F. Wong, is examining the brain chemistry of patients diagnosed with TS and/or OCD. Research subjects with TS and/or OCD as well as persons without these conditions are being recruited.

The research study will take place in Baltimore, Maryland. Individuals selected to participate in the study may be provided with resources for transportation, lodging, meals and reimbursement.

**Interested persons may direct questions to William Willis at [wwillis4@jhmi.edu](mailto:wwillis4@jhmi.edu) or 410-955-0210 for more information.**

*The Tourette Syndrome Association of Washington and Oregon, Inc. only provides information for the recruitment of research subjects for studies that endorsed by the by the Tourette Syndrome Association, Inc.*

## Professionals Coffee Chat - Pierce & Thurston Counties - Washington

Health and human service professionals (e.g., psychologists, educators, social workers, administrators) that work with persons with TS are welcome to chat over coffee and share programming and resource information on an on-going basis at 5:30 pm on the second Wednesday of the month in Tacoma. For more information, contact [henrytsawaor@aol.com](mailto:henrytsawaor@aol.com) or call (425) 350-3441.

## Summer 2010 South Puget Sound Picnic

Live in the South Puget Sound Area and interested in participating in a summer picnic with the TS community? We are looking at a location in the Tacoma area.

If so, email [henrytsawaor@aol.com](mailto:henrytsawaor@aol.com) and let us know.

## Back Issues of *Connections* Special Editions

Earlier this year, we issued two special editions of *Connections*. If you missed either of these newsletters and would like a copy, please email [henrytsawaor@aol.com](mailto:henrytsawaor@aol.com), and you may receive an electronic copy. Please provide the following contact information:

Email Address  
First and Last Name  
State and County of Residence

## Workplace Giving and TSA

Don't forget the Tourette Syndrome Association of Washington and Oregon, Inc. if you participate in "workplace giving". Another term for workplace giving is "payroll deduction"!

Our chapter is a member of **Community Health Charities of Washington and Idaho**. CHC of Washington and Idaho includes workplace giving campaigns in the Portland, OR metro area! For more information, visit the CHC of Washington and Idaho website at <http://washington.health-charities.org/>.

## Renew Your Membership in TSA and TSA of Washington and Oregon

Please make sure to renew your membership! When you join TSA, you automatically become a member of the Washington and Oregon Chapter. Your membership fees are an important source of revenue to your local TSA Chapter – TSA Washington and Oregon.

If you have not renewed your membership within the past year, please do so. You may renew your membership on-line by visiting: <http://tsa-usa.org/give/>

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<p><b>Join the Tourette Syndrome Association!</b></p> <p>When you join TSA, you automatically become a member of the Washington and Oregon Chapter. As a TSA chapter, most of our operating revenue comes from membership fees.</p> <p>It's easy to join on-line: <a href="http://store.tsa-usa.org/membership.html">http://store.tsa-usa.org/membership.html</a></p>	<p><b>Mailing Address:</b> 318 West Galer St., Suite B Seattle, WA 98119</p> <p><b>Information &amp; Referral line:</b> (206) 621-2108</p> <p><b>Washington Email:</b> <a href="mailto:tsawashingtonchapter@yahoo.com">tsawashingtonchapter@yahoo.com</a></p> <p><b>Oregon Email:</b> <a href="mailto:tsaoregon@yahoo.com">tsaoregon@yahoo.com</a></p> <p><b>Website:</b> <a href="http://www.tourette.net/wa">www.tourette.net/wa</a></p>	<p><b>Board of Directors:</b> Todd Henry, <i>Chair</i> Erin Farrar, <i>Vice Chair</i> Bernadette Witty, <i>Secretary</i> Carroll Frye, <i>Treasurer</i> Justin Clar Margaret Elofsen Brad Hawkins Carole Jones Holsey Satterwhite</p>	<p><b>Professional Advisory Board:</b> Jack Arrell Sheila M. Brommel, PhD, LISW Tim Dyck, MSW Michelle R. Henry, RN, BSN, BS Stan Jeppesen, Pharm.D. George Lynn, MA, MPA, LMHC Ala Mofidi, PhD, MBA David Pomeroy, MD Gregory N. Southworth, MBA, MS, LPC Sharon Thetford, Ph.D. Samuel Zinner, MD</p>
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**tourette syndrome association  
of washington and oregon, inc.**

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