

**Support Groups**

**Northend Seattle Network/support Group**

Coordinator: Please RSVP to Cathy at [mikecathym@aol.com](mailto:mikecathym@aol.com) or call (206) 546-8886  
 Date & Time: 2nd Monday evening of each month, 7:00-8:30 pm  
 Location: Calvin Presbyterian Church, 18826 Third Ave NW Shoreline, WA

**South Puget Sound Lunchtime Adult Network Group**

This is a network group for adults with TS and adult caregivers of children and adolescents with TS and associated conditions.  
 Coordinator: Todd Henry  
 Date & Time: Tuesday, November 4 and Tuesday, December 2, 11:30 AM  
 Location: Shari's Restaurant, 4525 Martin Way East, Olympia, WA (Martin Way Exit off I-5)

Must RSVP by contacting Todd Henry at (425) 350-3441 the Friday prior to the meeting.

**South Puget Sound Dinnertime Professionals Network**

This is a network group for health and human service professionals who serve persons with TS and/or associated conditions.  
 Coordinator: Todd Henry  
 Date & Time: Generally the second Tues or Wed of the month  
 Location: Restaurant near Tacoma Mall in Tacoma, WA  
 Must RSVP by the end of the month prior to the meeting by contacting Todd Henry at (425) 350-3441.

**South Puget Sound Network/support Group**

This group primarily focuses upon the needs of caregivers of special needs children, including those with ADHD, autism, Tourette Syndrome, OCD, learning disabilities, cerebral palsy, traumatic brain injury and/or other conditions.  
 Coordinator: Wyatt Holiday Foundation - To participate, one needs to join the Exceptional Families Network which is free of charge. Visit the Foundation's homepage: <http://www.wyattshouse.org/>  
 Date & Time: Most current dates and times are posted on the Foundation's website.  
 Location: Tumwater Timberland Library. Check the EFN schedule to verify date, time and location of meetings. Directions to the Tumwater Timberland Library may be found at: <http://www.timberland.lib.wa.us/tumwater.htm>

**Portland - Vancouver Area Network/support Group**

Coordinator: Erin (503) 293-5050, [tsaoregon@yahoo.com](mailto:tsaoregon@yahoo.com)  
 Date & Time: Sundays, Oct 19, Nov 16  
 All meetings are from 3:00pm - 4:30pm. Adults only if possible, please.  
 Location: Legacy Good Samaritan Medical Building, 2nd Floor Conference Room 1040, NW 22nd Ave, Portland, OR  
 The Medical Building is located directly across from Good Samaritan Hospital on 22nd Ave NW between Lovejoy and Marshall Streets. Enter front of the building - we are on the 2nd floor in the conference room on the left.



# Connections

Newsletter of the Tourette Syndrome Association | Washington and Oregon Chapter



November 1, 2008  
 ADHD Conference, Bellevue, WA

Tacoma-based Attention Deficit Disorder Resources is having a conference at the University of Washington in Seattle. The conference will be held at Smith Hall. William Dodson, M.D., will be the keynote speaker. For more information about registration, visit <http://add.obrienbusinessgroup.com/>.

November 24  
 Self-Advocacy: Understanding the Maze of Government Agency Administrative Law that Impacts Persons with TS and Associated Conditions

Persons with TS and associated conditions, the professionals that serve these populations and family and friends of persons with TS can help shape government policy regarding TS and related issues. Learn how you can monitor legislation that will result in government agency rulemaking that affects persons with TS and associated conditions, how the process works, and how to participate in the rulemaking process. You will learn how to researching statutes and administrative law (also called rules or regulations) on health insurance, pharmacy, health professions, human services, children's services, mental health and related topics.

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**Beginning January 1, 2009 Connections is Available via E-Mail Attachment: The Option is Yours!**

A number of our readers have requested *Connections* in electronic form. To be responsive, we will make the following option available: You can receive *Connections* either in electronic format (PDF) or paper copy via U.S. mail. The choice is yours.  
 If you request *Connections* in electronic format, we need to know the following information so that we can send it to you as an e-mail attachment. You will no longer receive paper copies of *Connections* after January 1, 2009.

Please email [tsawaormembership@yahoo.com](mailto:tsawaormembership@yahoo.com) to request future editions of *Connections* as an e-mail attachment. The subject line of your email should say "I want to be a *Connections* e-mail subscriber". Please include the following information in your email:

- email address or email addresses where you would like to receive *Connections*,
- your full name,
- your mailing address with ZIP Code, and
- current phone number where it is best to contact you.

By subscribing to the electronic version, you help the environment by reducing the amount of paper consumed, and U.S. mail delivered. Of course, you may always print a copy of *Connections* on your work or home computer printer.

Also, future special editions of *Connections* will be available at the time of publication only via email.

If you would like to continue to receive *Connections* in paper format, at this time you do not have to do anything. While not required, we encourage you to send in an annual donation of \$10.00 to receive a paper copy of *Connections*. This will help our chapter defray production, printing and postage costs. You may make a donation check payable to Tourette Syndrome Association Washington and Oregon State Chapter, and address the envelope to: TSA Washington and Oregon State Chapter, Attn: Connections Subscription, 318 West Galer St, Suite B, Seattle, WA 98119.

It is important to know that future editions of *Connections*, including special editions, will be posted to the chapter website so you can read them at a future date.

Regardless of what format you receive *Connections*, we encourage you to share this information with others so that the maximum number of persons benefit. We are regularly amazed at the journey some copies undertake when we receive a call or email from someone who is contacting us for the first time for information. ##

<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</p>	<p><b>Professional Advisory Board:</b>                  Jack Arrell                  Sheila M. Brommel, PhD, LISW                  Mark Chrisman                  Tim Dyck, M.S.W.                  Michelle R. Henry, RN, BSN, BS                  Stan Jeppesen, Pharm.D.                  George Lynn, MA, MPA, LMHC                  Ala Mofidi, PhD, MBA                  David Pomeroy, MD                  Holsey Satterwhite, MSW, Med                  Gregory N. Southworth, MBA, MS, LPC                  Sharon Thetford, Ph.D.                  Samuel Zinner, MD</p>
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**tourette syndrome association, inc.**  
 washington and oregon chapter

**CONNECTIONS**  
 122 Bond Road  
 Castle Rock, WA 98611

NONPROFIT ORG  
 U.S. POSTAGE  
 PAID  
 SEATTLE, WA  
 PERMIT NO. 02067

RETURN SERVICE REQUESTED

On Monday, November 24, 2008 from 6 pm to 8 pm there will be a two-hour workshop in Tukwila, WA. Please RSVP prior to confirm location and attendance no later than November 17. To RSVP, please contact (425) 350-3441. If you receive voice mail, leave your name and the telephone number (with area code) along with the number of persons who will be attending. A \$10 donation to the Tourette Syndrome Association-Washington and Oregon State Chapter is requested per attendee. At the end of the training, a certificate of completion will be given upon request.

#### Summer 2009, New York City

Attention Physicians, Scientists and Clinical Researchers! The 5th International Scientific Symposium on Tourette Syndrome, entitled Targeting Tourette Syndrome, will be held on June 11 through 13, 2009 in New York City. For registration information, visit <http://tsa-usa.org/news/0808SciSymposSvDt.html>.

Please share a copy of this newsletter with anyone that you believe might be interested in attending. ##

## Professionals who Work with the TS Community: Network Meeting

As a spill off of the lunch time network meetings held during 2007 in Thurston County, we will begin holding several dinner network meetings of persons who work with the TS and associated conditions community beginning this fall. Meetings will be held in Pierce County.

These will be informal gatherings to strategize about how to better meet the needs of persons with TS, ADHD, ADS, and other conditions, and how professionals, such as human service professionals, may better meet their needs.

For more information about dates, time and location, please leave a voice mail message at (425) 350-3441. Please leave your name, a phone number where it is best to contact you during the day and an email address. ##

## Managing Stress: Tips for Parents of Children with TS

By Cori Hartje and Michelle R. Henry

Parenting is a major responsibility. Parenting a child or teen with TS poses additional challenges. Sometimes parents of a newly diagnosed child with TS can feel overwhelmed. Even if your child was diagnosed a few years ago, challenges that seem to accompany Tourette Syndrome (TS) can seem to be never ending. In reality, all parents face stress. Here are a few tips that may make parenting any child, but especially a child with TS, less stressful.

- Recognize that everyone experiences stress at one time or another.
- Accept that some stress is good. Recognize that stress is part of life.
- Recognize that all parents face challenges in raising their child. No parent is perfect. No child is perfect.
- Ask for help to reduce stress in your life, and accept help.
- Set personal boundaries and limits about what you can do for others, and let others know what they are. For example, you don't have to answer the telephone each time it rings, or respond to every email you receive.
- Establish realistic goals and expectations for yourself.
- Establish realistic goals and expectations of others – including your children, significant other, child's school teacher, your child's neurologist, etc.
- Accept that some family routines might be somewhat different at times after your child's onset of TS. And this is ok.
- Accept that your child will have to come to terms with her/his TS. While you can help your child cope at times, ultimately she/he will have to develop her/his own ways of living with TS.
- A healthy, respectful sense of humor can often get you and your family through challenging times.
- Find support through understanding friends, support groups, or a professional counselor. TSA has support groups.
- Avoid people who you don't need to interact with if they are a source of stress to you. For example, avoid neighbors who you consider overly judgmental or critical if that causes you stress.
- Give yourself permission not to be perfect!

- Proactively provide structure to your child's homework routine—in order to reduce the number of last minute crises the night before a project or assignment is due!
- Practice deep breathing exercises, yoga, or meditation.
- Take time to tell your children you love them and show them love and affection.
- Keep a personal journal.
- Schedule personal time to catch your breath, gather your thoughts and/or be by yourself in a calm, peaceful environment.

*Cori Hartje, M.A., B.S., is a member of the chapter board, business woman and former educator. Over the years, Ms. Hartje has provided many trainings to educators and parents about TS. Michelle Henry, RN, B.S.N., B.A., is a member of the chapter professional advisory board. ##*

## FDA Website Provides Useful Information about Medications

By Todd Erik Henry

Almost everyone take medication at one time or another. Persons with Tourette Syndrome (TS) may take one or more medications to manage symptoms of TS and/or associated conditions. We often hear about mandated recalls of medications and voluntary recalls in the news media. However, many people want more specific information than listening to a blurb on the radio or television.

The U.S. Food and Drug Administration (FDA) website (<http://www.fda.gov>) is a great resource way to keep current about possible recalls, market withdrawals and safety alerts on prescription and over-the-counter medications.

The FDA even has a webpage dedicated to information about recalls, market withdrawals and safety alerts. This may be found at: <http://www.fda.gov/opacom/7alerts.html>. By visiting this webpage, you can read about recent recalls and other activity about various products, and even use a search tool to see if there have been past recalls or other actions.

If you want, you can even subscribe to e-mail notifications about FDA recalls and related information by visiting: [https://service.govdelivery.com/service/subscribe.html?code=USFDA\\_48](https://service.govdelivery.com/service/subscribe.html?code=USFDA_48). ##

## TS and Seniors

As we age, we tend to use more health care services. For senior citizens who enter long-term care homes, they may be diagnosed for the first time with Tourette Syndrome (TS), ADHD and/or other conditions for the first time in their lives. These individuals have learned to manage their symptoms as best they could, on their own, over their lifetime. Being diagnosed for the first time when admitted into long-term care may occur for a variety of reasons, including increased awareness today of TS and associated conditions, the fact these individuals are now receiving increased health care services where a physician can obtain a medical history and make a diagnosis, decreased ability to mask symptoms when visiting a health care professional, and/or ability of professionals to observe their behavior over an extended period of time.

In September, our TSA chapter had an information table at the 5th Annual Making the Case for Justice Conference in Bellevue, Washington. This conference is sponsored by the King County Prosecuting Attorney's Office. The conference is about investigation and prevention of crimes against elders and vulnerable adults. This is a two-day conference for health and human service professionals working with the elderly in their own homes and in various care settings.

A number of long-term care homes in Western Washington that were represented at the conference have expressed an interest in learning more about TS and associated conditions. The reasons vary. More long-term care residents are now being diagnosed with TS, ADHD, OCD, and the like. Working in long-term care settings can be frustrating for caregivers. Caregivers who are not properly trained to recognize or understand TS may be more likely to abuse persons with TS.

A special thanks to the King County Prosecutor's Office for sponsoring this important event! As the population ages, raising awareness about TS among lay persons and professionals is increasingly important. If you are a long-term care home administrator or director of nursing services in Oregon or Washington who would like to obtain more information about TS, please contact our chapter by telephoning (425) 350-3441. We will gladly mail you information that you may distribute at staff meetings/in-service training sessions. ##

## Helpful Sources for General Info about TS on the Web

When you need to explain what Tourette Syndrome is to an educator, neighbor, family member, friend, employer, co-worker or the like, it is helpful to be able to print up information that is from a source YOU trust and a source they will trust and respect as well. Here are several excellent web resources where you can find information about TS:

Centers for Disease Control and Prevention (CDC)  
<http://www.cdc.gov/ncbddd/tourette/default.htm>

Cleveland Clinic  
[http://my.clevelandclinic.org/disorders/Tourette\\_Syndrome/hic\\_Tourette\\_Syndrome.aspx](http://my.clevelandclinic.org/disorders/Tourette_Syndrome/hic_Tourette_Syndrome.aspx)

Mayo Clinic  
<http://www.mayoclinic.com/health/tourette-syndrome/DS00541>

National Institutes of Health, National Institute of Neurological Disorders and Strokes  
<http://www.ninds.nih.gov/disorders/tourette/tourette.htm>

Tourette Syndrome Association  
[www.tsa-usa.org](http://www.tsa-usa.org)

Washington University Physicians (Saint Louis, MO)  
<http://wuphysicians.wustl.edu/dept.aspx?pageID=13&ID=4>

Yale University School of Medicine  
<http://info.med.yale.edu/chldstdy/tsocd/>

## Finding a Neurologist

Some persons who have been diagnosed with TS see a neurologist periodically. Our TSA chapter is frequently asked for the names of neurologists who are familiar with TS. Selection of a neurologist, like any health care professional, is a complex decision.

The American Academy of Neurology has an on-line tool that can be helpful for identifying neurologists in your local community. This tool may be found by visiting <http://www.thebrainmatters.org/index.cfm?key=1.2.2> ##

## Fiscal Year 2007 Annual Report

Our chapter's first annual report has been produced. In order to keep our costs down, the report will be distributed via email to persons who are on our chapter email list. The report will be posted on our chapter website in the near future. ##

## Interested in Joining the Board?

Our chapter is periodically looking for new board of director members. To be considered for the board, you don't have to be a person with TS or a family member of a person with TS. Board members can be anyone who has a sincere interest in TS and related issues.

We need board members from across Oregon and Washington, especially the eastern portion of both states.

Board meetings are generally held monthly. The board meets in person about five times per year. The remaining board meetings are held via conference call.

The board holds the majority of its in-person meetings in King County, WA. The board's annual strategic planning board meeting is moved to different locations in Western WA and Western OR.

If you are interested in learning more about the board and applying to join the board, please contact: (425) 350-3441. Please leave our full name, city and state where you live, phone number where it is best to contact you and an email address. ##