



tourette syndrome association, inc.  
washington and oregon chapter

# CONNECTIONS

Newsletter of the Washington and Oregon Chapter of the Tourette Syndrome Association



Volume XIII, Issue 2

Fall 2006

## TS Now Recognized under IDEA!

"It finally happened!" says TSA Washington & Oregon Vice President and Legislative Liaison, Todd Erik Henry. "The U.S. Department of Education has completed their final regulations enforcing Part B of IDEA. Tourette Syndrome TS is now listed as a disability under the category of 'Other Health Impaired.' This is an important victory for children with TS."

IDEA stands for Individuals with Disabilities Education Act. On August 3, 2006 U.S. Department of Education Secretary Margaret Spellings announced the release of the Final IDEA Part B 2004 Regulations. The regulations are approximately 1700 pages in length. The Department of Education solicited input from educators and the public in meetings held around the nation, as well as in written form.

Other Health Impaired is often referred to by its acronym, OHI. "For those interested in seeing for themselves," says Henry, "Tourette Syndrome is mentioned on page 4 of the first preamble section and pages 63-65. Also, TS is mentioned as an OHI in the section on pages 1263-1264."

The efforts of countless TS advocates for over a decade have been critical. The work of the national TSA chapter is deeply appreciated.

TSA has literally held hundreds of meetings with members of Congress and their staff and officials with the U.S. Department of Education. TS advocates and TSA members have sent thousands of letters over the years to members of Congress asking that TS be included as an OHI.

Further, in her discussion of the new regulations, Secretary Spellings specifically acknowledged Tourette Syndrome as an example of one of the changes that were made. Secretary Spellings referred to TS as a neurological disorder, not a behavioral issue.

So why is inclusion of TS as an OHI so important? Here is a brief response: IDEA classification category frequently dictates a child's classroom placement, services provided and behavioral intervention plan.

Unfortunately, many teachers and school psychologists and school nurses educators, continue to see TS as a behavioral or conduct disorder because of the nature of its symptoms. Educators therefore classify children with TS under the Emotionally Disturbed (ED) category, when they have a neurological disorder.

Incorrect classification of a child with TS frequently results in students being placed in programs that are designed for students with emotional disorders where bullying and

teasing generally increase as does the punishment for their symptoms.

With TS now appropriately listed under the category of OHI, students with TS will be entitled to fair treatment under their condition under federal law.

Says Henry, "Parents of children with TS, and other TS advocates will play an important role in bringing this information to teachers, school administrators and others about this important development in federal education law."

On August 14, the official copy of the Part B regulations was published in the Federal Register. You may access the Federal Register at: <http://www.gpoaccess.gov/fr/index.html>

More information about this important development will follow in future issues.

Information on IDEA at the U.S. Department of Education website may be found by visiting: <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>

## PRESIDENT'S REPORT

by Bernadette Witty, Chapter President



Hello Chapter Members!

I hope everyone had a wonderful summer and I am sure you are all busy adjusting to the changing seasons. May and June were extremely busy months for our chapter and I invite you to read about the many events held over "Tourette Syndrome Awareness Month" which ran from May 15 to June 15. We received great feedback on the range of events that we offered and we tried to choose a variety of events that held a wide range of appeal. I know we probably would have had a larger turnout had people got the information a little earlier, so please accept our apologies to those who received the flyers a little late. Actually it is much easier, faster as well as cheaper to send out these news events via email. We are all volunteers, doing the best we can and sometimes things get arranged rather last minute, so if we could communicate via email, it would make it much easier for the event organizers. **So, if you would like to receive information in a more timely manner, please send us your email address and we can add you to our mailing list (or verify we have the correct email for you.)** We promise that we will not under any circumstances disclose your email address to any outside organization so you would not have to worry about getting junk mail as a result of us. It would really help us tremendously. We have a few more events in the initial planning stage, so please stay tuned and in the mean time check our website for updates.

I hope you enjoy this issue and I hope to meet you at some point at a chapter event.

Tourette Syndrome Association  
Washington and Oregon Chapter

**Mailing Address:**  
318 West Galer St., Suite B  
Seattle, WA 98119

**Information & Referral line:**  
(206) 621-2108

**Washington Email:**  
[tsawashingtonchapter@yahoo.com](mailto:tsawashingtonchapter@yahoo.com)  
**Oregon Email:**  
[tsaoregon@yahoo.com](mailto:tsaoregon@yahoo.com)

**Website:**  
[www.tourette.net/wa](http://www.tourette.net/wa)

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**About This Issue:**

CONNECTIONS is the newsletter of the Washington and Oregon Chapter of the Tourette Syndrome Association. The next issue will come out in Winter 2007.

**To help us keep our costs down, we ask that if you would no longer like to receive this newsletter, please let us know.**

If you have any written contributions or suggestions for the next issue, send them to the following address by November 15:

*Tourette Syndrome Association  
Washington and Oregon Chapter  
Attn: Carole Jones, Newsletter  
318 West Galer Street, Suite B  
Seattle, WA 98119*



## Tourette Syndrome Awareness Month

*by Bernadette Witty*

May 15 to June 15 was Tourette Syndrome Awareness month. For the first time, our chapter held and supported

twelve events during Awareness month. It was a lot of work but we feel the expanded awareness and improved understanding that we generated as a result was worth the many hours of effort it took to pull the events together! We would like to thank everyone who attended these events and supported our chapter.

### Saturday May 6, 2006 - HBO film Screening:

We started awareness month a little early with a screening of the HBO family documentary "I have Tourette's but Tourette's doesn't have me." This was held at Northwest Hospital in Seattle. We showed the movie in a great auditorium on a wall sized screen and followed with an informal question and answer and discussion session. The event was attended by approximately 25 adults and 8 children. We received great feedback from the attendees who not only enjoyed the movie but also enjoyed the discussion afterwards which covered topics including education among the medical and school communities, more screenings of the HBO movie and various experiences with TS among other things. This movie has a powerful message to send and is a great opening point for discussion of Tourette Syndrome. I think every child and family should see this movie, regardless if they live with TS or not. If you would like to organize a screening in your local area, please contact us and we can help you.

### Thursday May 18, 2006 – Senior project on TS presentation:

**Erik Frandsen**, a high school senior at International School of Bellevue, chose Tourette Syndrome as his topic for his high school senior project. On May 18 he gave a presentation on Tourette syndrome to an audience of around 30 including his teachers and peers as the culmination of his year long project. He gave an excellent multi-media presentation on Tourette Syndrome not only including the basic facts and symptoms but tackling some of the more involved scenarios including the many co-existing conditions that come along with TS. He talked about his research and findings and his experiences going out to schools and working with kids with TS as part of his project. As a young adult with TS he also gave some of his personal experiences that really helped explain things at a deeper level. He gave a very professional presentation and answered questions comfortably and easily. This was not a chapter organized event but was attended by the Chapter President, board members, chapter members and our chapter medical advisor Dr Sam Zinner. A few weeks later, **Cathy Marinella** who is a chapter member, leader of the North End Seattle support group and a parent of a child with TS was asked to be one of the judges on his project. We are very pleased that the school invited our chapter to offer someone with personal experience with TS to be on the judging panel. Erik received top marks from us because his project and presentation was of exceptional standard. We would recommend others to consider Tourette Syndrome as a topic for your high school project. If you would like further information about his senior project, you can contact Erik at [ketch87@hotmail.com](mailto:ketch87@hotmail.com)

### Sunday May 21, 2006 – Kick-off for the “What Makes Me Tic” Project:

Laura Fixler is a chapter member who is excited about a new self-advocacy program for youths with TS called the “What Makes Me Tic” project. She was inspired to start this after her brother gave a compelling and heart-felt presentation to his school explaining Tourette Syndrome and his experiences in living with it. Laura witnessed the powerful effect that self-advocacy can achieve and would like to help other youths with TS do the same. She held a kick-off meeting on May 21st at the Green Lake branch of the Seattle Public Library with five adults and one young adult attending. If you would like more information on this contact Laura at [whatmakesmetic@yahoo.com](mailto:whatmakesmetic@yahoo.com)

### Sunday May 21, 2006 – Portland support group meeting:

The Portland support group is a very active one and is led by board member **Erin Farrar**. They held their meeting on May 21st in Portland, Oregon with twelve adults attending. For more information on this support group contact: [tsaoregon@yahoo.com](mailto:tsaoregon@yahoo.com)

### Friday May 26, 2006 – HBO film Screening on Bainbridge Island:

Another screening of the HBO family documentary “*I have Tourette’s but Tourette’s doesn’t have me*” was held on May 26 at the home of Chapter Chair, **Bernadette Witty** on Bainbridge Island. The event was attended by nine adults and fourteen children including some that knew a lot about TS, some a little and some with no prior knowledge. The movie had a profound effect on both adults and children which prompted some great post-movie discussion as well.

### Thursday June 1, 2006 – Grand Rounds at Seattle Children’s Hospital:

A Grand Rounds presentation on Tourette Syndrome was given by **Dr. Sam Zinner** on June 1st at Seattle Children’s Hospital & Regional Medical Center. This was organized by National TSA and funded as part of the 1.6 million dollar grant to the Center for Diseases Control (CDC) and National TSA for the Tourette Syndrome Public Health and Education program. While I do not have exact numbers of attendees, there looked to be at least forty doctors and medical professionals in attendance. Dr. Zinner gave an excellent presentation and we are glad that another segment of the medical profession has been educated on Tourette Syndrome. This grant is the one that you have probably received emails from us asking you to call your senators and house representatives to support. It is through this federal grant that this Grand Rounds was funded as well as a similar one also given by Dr. Zinner at Oregon Health and Science University in Portland Oregon last year. These are two good reasons to keep reminding our legislators how important this grant is!

### Thursday June 1, 2006 - Government Relations Day

**Todd Henry**, Chapter Vice President and **Bernadette Witty**, along with her three children held four meetings in Olympia on June 1st with aides of key State Senators and State representatives in the health care field to talk about issues related to Tourette Syndrome. The meetings were very positive and we were glad to have educated some of our state government officials on Tourette Syndrome and talked to them about the issues relevant to our community. This is the first time we have participated in the official “Government Relations Day” which is held by chapters across the country and I would highly recommend others to join us next year. We may even plan further visits to our legislators throughout the year and perhaps visit their local offices which may be geographically more convenient for many. For offers to join us on these visits or any questions related to legislative issues contact our Chapter Vice-President and Government Relations Liaison **Todd Henry** at [chelle.todd@comcast.net](mailto:chelle.todd@comcast.net)

### Thursday June 1, 2006 – Seattle Support Group meeting:

A number of months ago we were pleased to announce the start of a new support group in Seattle. They held their second meeting on June 1st at the Calvin Presbyterian Church in Shoreline. Six adults attended and held a great discussion and shared experiences and insights in living with TS in their families. For further information on this support group contact **Cathy Marinella** at [mikecathym@aol.com](mailto:mikecathym@aol.com)

### Thursday June 8, 2006 – TS Q&A: Ask the Expert session:

We had the great fortune to offer an informal “TS Q&A: Ask the Expert” session on June 8th at Seattle Children’s Hospital and Regional Medical Center. Samuel Zinner, M.D. and George Lynn, M.A., M.P.A., L.M.H.C., offered their time to us for an informal question and answer session. Eight adults attended and through their various questions a wide range of topics were discussed as well as a number of resources and contacts provided. It was a great session for those who attended who had a number of their pressing questions addressed.

### Saturday June 10, 2006 – 2 HBO film Screenings in Portland:

Two screenings of the HBO family documentary “*I have Tourette’s but Tourette’s doesn’t have me*” were held in Portland Oregon. One was held at SW WA Medical Center in Portland, with fifteen adults attending and the second was held at the Legacy Good Samaritan Hospital with seven adults attending. The response to both events was very positive. For more events in the Portland area contact [tsaoregon@yahoo.com](mailto:tsaoregon@yahoo.com)

*continued on page 8*

## EDUCATION NEWS

### Earning a Certificate of Individual Achievement (CIA): Information for Special Education Students and Their Families in Washington State

Reprinted from the OSPI website:

<http://www.k12.wa.us/graduationrequirements/CIA.aspx>

All students in Washington have an opportunity to earn a standard diploma.

Beginning with the Class of 2008, one of the requirements for graduation for all students is to earn a Certificate of Academic Achievement (CAA) or a Certificate of Individual Achievement (CIA).

To earn a CAA, students must meet standards in reading, writing and mathematics as demonstrated on the Washington Assessment of Student Learning (WASL) or through an alternate method.

The CIA was created for students in special education programs who are not appropriately assessed by the WASL. To earn a CIA, a student must meet proficiency standards based on requirements that are specified in the student's Individual Education Program (IEP). (Students with a Section 504 Plan are not eligible to earn a CIA.)

Many special education students are able to participate in the WASL or the alternative – with or without accommodations – and earn a Certificate of Academic Achievement. However, meeting one or more standards on the high school WASL may present significant challenges to some students with special needs. For these students, modified and alternate assessments are available.

The IEP team, including the student, makes the decision about whether or not a student qualifies for taking a modified or alternate assessment. Information gathered from several sources may be used to make choices about what options are most appropriate for a student. Students can provide important information to the IEP team about their abilities and goals for the future. Information about the student's plans after leaving high school (college/adult training programs, competitive/supported employment, independent/ supported living) may help guide the IEP team. The student's instructional program and his/her progress toward IEP goals also facilitates the decision-making process. Finally, review of past performance on state and district assessments and other evaluations can also provide valuable information in making a decision.

There are multiple testing options available for IEP teams to consider that will allow students to earn a CIA. They include:

1. Taking the 10th-grade WASL and passing at Proficiency Level 2 (Basic). This is known as the "Washington Alter-

nate Assessment System-Developmentally Appropriate WASL" (WAAS-DAW) Proficiency Level 2.

2. Taking the WASL at a different grade-level. For some students with mild disabilities, taking a WASL at a level that is more closely aligned with a student's measured academic ability may be the best option. For example, the IEP team may determine that the seventh-grade WASL may be the most appropriate and challenging option for a high school student in reading.

3. For students with more significant disabilities, the IEP team may determine that the Washington Alternate Assessment System Portfolio (WAAS-Portfolio) is the most appropriate assessment option. The WAAS-Portfolio is a collection of evidence demonstrating progress on IEP-related skills and the generalization of these skills to other environments.

4. For a small number of students with very unique circumstances, the IEP team may need to consider other appropriate measures for assessment. These alternate plans will be developed and reviewed on an individual basis and determined jointly by the IEP team and Office of Superintendent of Public Instruction.

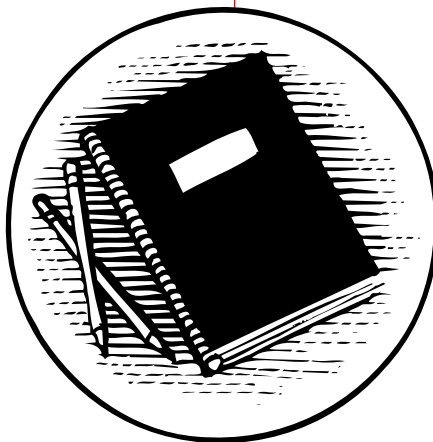
The IEP team may consider these options by content area. In other words, it is possible for a student to take the WASL with or without accommodations in mathematics, take the "WAAS-DAW" at Level 7 in reading, and take the "WAAS-DAW: Proficiency Level 2" in writing. Portfolio options can be considered for different content areas of the WASL as well. In addition, all students can retake assessments multiple times if they do not meet proficiency standards.

Earning a CIA will lead to a standard diploma. The difference in the certificate will be noted only on the student's transcript.

Students earn a Certificate of Academic Achievement only by passing the high school WASL in reading, writing and mathematics (and, for the graduating class of 2010 and beyond, in science). Students enrolled in special education programs can take a combination of assessments – including the WASL and those designed for special education students – based on the guidelines in their individualized education programs, but passing any combination of these assessments will result in a Certificate of Individual Achievement, not a Certificate of Academic Achievement.

#### For more information:

- "Guidelines for Participation and Testing Accommodations for Special Populations in State Assessment Programs" <http://www.k12.wa.us/Assessment/TestAdministration/publications/GuidelinesSpecialPopulationsStateTests2005>
- Special Education Assessment <http://www.k12.wa.us/SpecialEd/assessment.aspx>



SEATTLE POST-INTELLIGENCER

## Attendance has Never Been Optional for Blake Kenyon

Monday, June 19, 2006

By CECELIA GOODNOW, PI REPORTER

Sometimes the hardest thing in life is just getting out of bed and traveling, once more, the well-worn path.

Blake Kenyon has done it every day for 13 years, racking up perfect attendance from kindergarten through high school despite hurdles that most kids don't have to face.

Kenyon is many things:

- A starting lineman on Skyline High School's state championship football team in Sammamish.
- A beefy kid who can bench-press 185 pounds, and do 35 reps.
- A college-bound young man who's thinking of becoming a lawyer.

"That's what my dad does," said Kenyon, a serious, focused kind of guy, "and I respect him."

In kindergarten, the same year Kenyon started on the perfect-attendance track, a neurologist diagnosed him with Tourette's syndrome, a condition that causes recurrent physical and vocal tics. The first time it happened, his kindergarten teacher thought he was having a seizure. Kenyon's parents got him to the doctor that same day.

Like a lot of people with Tourette's, Kenyon also has obsessive-compulsive disorder. For a while he stuttered as well, and he still has fine-motor problems that slow his writing and make it hard to pencil in those little standardized-test bubbles.

Ultimately, his determination to show up for school every day says more about him than the disorders that could have derailed him. "He's probably the hardest-working student I've ever worked with," said Mathew Taylor, a special education teacher and assistant football coach who has worked with Kenyon the past four years. "All these years there's got to be some class he didn't like ~ but he still went. He's an awesome young man."

Kenyon, 18, said his quest for perfect attendance began as a way to top his father's record. "My dad never missed a day of school up to fifth grade," he explained, parking his husky frame on a delicate, antique chair in his mom's office at Pacific Galleries, a Sodo antiques mall and auction house. "He said if I could beat him, he'd give me a pretend sick day - buy me a video game or something."

Kenyon rose to the challenge and kept on truckin', all the way through high school - though he never did get that video game. He hopes to repeat the pattern at Western Washington University, where he plans to major in political science.

Admittedly, temptations lurked on the road to perfect attendance, such as invitations to join his buddies on ski trips and jaunts to Mexico, or trips to Europe with his mom and sisters. "I have a lot of cool friends," Kenyon said, "and they organize a lot of senior skip days." But he ignored the distract-

tions and soldiered on, without regret. "If I missed school, I'd probably be disappointed in myself," he said, halting midway through the last word, as if hesitant to admit how much it meant to him. Even Europe proved surprisingly easy to pass up. "I don't want to go to Europe," Kenyon said bluntly. "I don't want to leave America. I love it."

Truth be told, for someone with Kenyon's makeup, a certain amount of same-old, same-old has its advantages. "I don't like changes thrown in there that I don't know about," he said. Just coping with the unpredictability of his body is challenge enough. People with Tourette's syndrome, a childhood-onset disorder, are beset by repetitive, largely involuntary movements and vocalizations called tics, which tend to wax and wane over time.

Typical examples include rapid blinking, grimacing, shoulder shrugs, clacking, hissing or repetitive phrases such as "oh, boy." Coprolalia, the involuntary utterance of profanities or slurs, is a relatively rare form of the syndrome and doesn't affect Kenyon. His own tics, which peaked in seventh grade, revolve around clapping, tapping and hand wringing. He also used to make a sss-sss-sss sound, like brushes on cymbals. Sitting in his mom's office, he demonstrated, hunching over in the chair and screwing up his face.

Kenyon's finger tapping also has an obsessive-compulsive component, because he feels driven to distribute the finger taps evenly between his left and right hands, to "make everything even." He also tends to avoid the number 6. Offer him a cupcake from a six-pack, for instance, and he'll likely decline until someone else takes one first, leaving five. "I got obsessed with making sure everything was a good number," he said. You wouldn't know this to look at him, though he does have a serious, reined-in manner. He speaks rapidly, in the terse, mumbly way of teenage boys.

Dark-eyed, with neatly buzzed dark hair, he's popular, well-mannered and bright. Last year he got A's and B's in an academically challenging International Baccalaureate biology class. Kenyon's symptoms have grown more subtle over the years. Like a lot of people with Tourette's, he has some control over his tics. "When I really focus on them, I can control them," he said. "But if I am excited or really just 'out there,' not paying attention to anything, I'll have a Tourette attack. Or if I'm really bored." When that happens, he prays. "I ask God for strength to get over them."

Kenyon is more devout than the rest of his family and has considered becoming a pastor. But he says: "I'm not sure if I have what it takes to be a pastor. I'm not sure if I have enough life experience."

What he does have is determination, backed by a high-achieving family. His mom, Lynn Kenyon, is general manager at Pacific Galleries and editor of *Fine Interiors* magazine. His dad, Mike Kenyon, owns his own law firm; last week he was arguing a case before the state Supreme Court. Older sister Rachel was class valedictorian at Blake's school. Younger sister Alex is the cheer captain. "We have high expectations for Blake," Lynn said, "and he has high expectations for himself." Blake cringed, thoroughly mortified. "Lynn," he growled. "Leave. I mean it."

*continued on page 6*

*Attendance has Never Been Optional continued from page 5*

His mom smiled but stayed put. As she had said in an e-mail a few days before, "He is quite humble and would never boast."

For Taylor, the teacher, bidding farewell to a student who has worked so hard and come so far will be bittersweet. "I'm really going to miss him a lot," Taylor said. "I can't say enough good things about him." On Tuesday, Kenyon and his classmates will experience the climax of their high-school careers - their graduation ceremony at Safeco Field. Earlier that day, Skyline High is hosting a senior breakfast and awards ceremony. Attendance is optional - a laughable concept for a hard-working guy with a record to maintain.

Miss it? Not for the world. "He'll be there," his mom said with a knowing laugh.

**RESOURCES**

**TOURETTE SYNDROME:**

[www.ninds.nih.gov](http://www.ninds.nih.gov): National Institute of Neurological Disorders and Stroke. (To find Tourette's, click on T in the index at the top of the page.)

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

Official site of the national Tourette Syndrome Association.

**OBSESSIVE-COMPULSIVE DISORDER:**

[www.ocfoundation.org](http://www.ocfoundation.org): The Obsessive Compulsive Foundation.

[www.nimh.nih.gov](http://www.nimh.nih.gov): National Institute of Mental Health.

*PI reporter Cecelia Goodnow can be reached at 206-448-8353 or [ceceliagoodnow@seattlepi.com](mailto:ceceliagoodnow@seattlepi.com). © 1998-2006 Seattle Post-Intelligencer*

**National TSA Website Adds Seattle Physician Lecture to Continuing Medical Education (CME) Offerings**

Seattle physician, Samuel H. Zinner, M.D., is featured on the TSA national website. His presentation, "TOURETTE SYNDROME: Tackling a noisy tic disorder without a whisper about medication," is available via the webstream. This lecture was initially given on June 1, 2006 the Children's Hospital and Regional Medical Center in Seattle, Washington. Visit <http://www.tsa-usa.org/> to register and view.

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**12890 NE 15th Pl., Bellevue, Washington**

**425.453.3272**

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**Ari Grashin Memorial Award Presented to Andrew Lyon**



In 2005, the Paul Robeson Scholar-Athlete Awards program announced the creation of the Ari Grashin Memorial Award in honor of a scholar-athlete who led by example, never gave up and continued to reach for his goals. A former three-time award recipient who passed away in 2002 at the age of 16, Ari was an inspirational young man who while battling cancer continued his commitment to excellence. The Ari Grashin Memorial Award is a fitting tribute to a local youth who inspired many with his positive attitude and encouragement.

This year, the Paul Robeson Scholar-Athlete Awards program was pleased to present the Ari Grashin Memorial Award to Andrew Lyon. An inspiration to his family and friends, Andrew has lived a life of many challenges. At the age of six, Andrew suffered an unusually severe and life threatening case of osteomyelitis. Due to this illness, he started grade school in a wheelchair with intravenous antibiotics. Despite surgery and learning to walk again, Andrew played many sports and developed significant skills in soccer and baseball.

When he was eight years old, Andrew was diagnosed with Tourette Syndrome, a neurological disorder characterized by uncontrollable vocal and motor tics. Most children with the disorder also experience symptoms of attention deficit disorder, obsessive-compulsive disorder, learning disorders and depression. The Tourette's worsened through adolescence and he struggled to maintain friendships and good grades amidst constant embarrassment, isolation and harassment.

Andrew faced each challenge head on and was never willing to quit. Maintaining his enthusiasm, he has consistently taken risks and challenges himself in school, sports and social situations. Today Andrew participates in programs that teach advocacy for the disabled, is a goalie for his soccer team, performs in school musicals, volunteers for school projects and fund raisers and was chosen "Junior Male with Most School Spirit." He looks forward to attending college and exploring the many career options that await him.

Much like Ari Grashin was during his lifetime, Andrew Lyon is a go-getter who exhibits character, determination, and a tenacious drive to succeed. The Paul Robeson Scholar-Athlete Award was a motivator to Ari and continues to be a motivator for Andrew. Andrew appreciates the challenge of sports and the commitment it takes to succeed. He also knows the importance of education and balancing success on the playing field and in the classroom. Congratulations, Andrew!

# Your Student Can DO-IT!

by Nanette Rosenthal

DO-IT (Disabilities, Opportunities, Internetworking, and Technology) is an outreach program housed at the University of Washington which serves to increase the participation of individuals with disabilities in challenging academic programs and careers. It promotes the use of computing and networking technologies to increase independence, productivity, and participation in education and employment. It serves high school and college students with a wide range of physical and learning disabilities, including those with TS, ADHD, Asperger's and other conditions. Participants need only to be cognitively capable of the academic demands of school.

There are many different programs housed within DO-IT as well as an incredible variety of print, video and internet resources that they have developed which help students learn what accommodations are out there to assist them, how to access those accommodations, how to make the transition from high school to college and a career, and how to advocate for themselves in the classroom or job setting. Three of the programs which DO-IT has developed are described below.

## DO-IT Scholars

Each year 20 Washington State high school sophomores, juniors or freshman are chosen through an application process to be DO-IT Scholars (in that order of priority). These students:

- Explore careers and the world of work
- Learn to select and use adaptive technology
- Experience college life at the UW campus in the summer
- Learn about reasonable accommodations at school and in the workplace
- Network with peers and working professionals with disabilities
- Gain prerequisite knowledge to enter and succeed in college and challenging careers

## The Scholars program consists of three phases.

Phase I Scholars participate in a two-week summer live-in program at the UW where they participate in lectures and labs, live in dorms and practice skills to help them be independent and successful in a college setting. Throughout that first year, they also learn how to use computers to enrich their education and to explore academic and career interests using the internet. They communicate frequently with the other Scholars and with Mentors who are college students, faculty and practicing professionals, many with disabilities themselves. If a Scholar does not have the necessary computer equipment, it is loaned to him/her while he/she is active in program activities.

Phase II Scholars come back to the UW campus the following summer for one-week live-in program to create and

complete projects of personal interest. Throughout the year they apply their interests, skills, and knowledge to design and complete independent and team projects. DO-IT Mentors and staff act as resources. They also continue frequent email communication with other Scholars and practice their leadership skills by acting as peer Mentors for Phase I Scholars.

Phase III Scholars can continue to contribute to the DO-IT community through individual activities including developing programs, contributing to the DO-IT newsletter and assisting with summer camps.

Applications are sent out to the special education departments of all Washington high schools in the fall. The application packet is due January 10. If you cannot get an application from your child's high school, contact DO-IT's offices directly at 206-685-3648 or 888-972-3648 outside the Seattle area.

## DO-IT Pals

DO-IT Pals are teens with disabilities who want to attend college, would like to meet other teens with similar goals, and would like to get tips for success from college students and other adults with disabilities. They participate in an electronic community with other

Pals and Mentors, motivating each other to achieve their goals. They apply their knowledge and skills by completing projects based on their interests with help from Mentors and DO-IT staff. Examples of possible projects include: completing an exhibit or a paper about adaptive technology or people with disabilities for a school assignment; being a mentor to a younger student with disabilities in the community, etc. Pals are invited to DO-IT events a couple times a year which are held throughout the state. DO-IT Pals must have their own computer equipment to access the internet.

To find out more about this program, contact DO-IT at [doit@u.washington.edu](mailto:doit@u.washington.edu).

## Career Opportunities

DO-IT has three programs that help high school and college students with disabilities participate in work-based learning experiences such as internships, cooperative education, job shadowing, service learning, independent study, and informational interviews, DO-IT CAREERS, AccessComputing and AccessSTEM. DO-IT CAREERS offers career planning and preparation and helps the student develop self-determination, self-advocacy and work-readiness skills. AccessComputing is more specifically for students interested in computing fields, and those students are eligible for work-based learning experiences. AccessSTEM is for students who are interested in pursuing a career in the fields of science, technology, engineering or mathematics. Work-based learning experiences are also available. Students must have an email account and access to the Internet to participate. Applications are available upon request at DO-IT, [doit@u.washington.edu](mailto:doit@u.washington.edu) or 206-685-3648.

*continued on page 8*

*Your Student Can DO-IT! continued from page 7*

## DO-IT Resources

DO-IT's website also has a vast amount of information and resources on it for students and adults and with disabilities. All of the brochures they publish are available on their website or for free upon request. Their videos are available in a streaming format on their website or for a low cost in DVD format. Their website is <http://www.washington.edu/doi/>

Topics on their website focus on issues for people with disabilities, including access to technology, science, mathematics, engineering, postsecondary education, and careers. Popular links from the home page include those to:

- \* AccessIT, the National Center on Accessible Information Technology in Education
- \* AccessSTEM, the Regional Alliance on Access to Science, Technology, Engineering, and Mathematics
- \* The Faculty Room, a resource to help postsecondary faculty make their courses accessible to students with disabilities
- \* AccessCAREERS, a center of programs and resources that promote work-based learning opportunities for high school and college students with disabilities.

*Tourette Syndrome Awareness Month continued from page 3*

## Tuesday June 20, 2006 - HBO film Screening & Silent Auction on Bainbridge Island:

Another screening of the HBO family documentary "*I have Tourette's but Tourette's doesn't have me*" was held at Bainbridge Cinemas at the Pavilion, Bainbridge Island. Twenty adults and ten children attended, representing a range of community members including the general public, teachers, nurses and chapter members. We had a great post-film discussion in the movie theater and a number of great contacts were made. We also held a silent auction as a fund-raising effort to support our chapter. I would like to thank once again the Bainbridge Island businesses who were so generous in their donation of auction items.

So all in all, it was a very busy and successful Awareness month. Next year we would like to expand it and gain greater press coverage of Tourette Syndrome awareness month. If you think you can organize an event in your local area, please let us know. Most of the events were in the Seattle, Portland and surrounding areas and we would really like to expand events to other parts of the state. It is hard for us to do that without people in those areas so your help on this is really needed. Please contact us at [tsawashingtonchapter@yahoo.com](mailto:tsawashingtonchapter@yahoo.com) to help. Thank you!

## The "What Makes Me Tic" Project

by Laura Fixler

In his early adolescence my brother was struggling in nearly every area of his life. His parents were divorcing, he was attending school less than half of the time and drugs were becoming his only solace. The fact that he had Tourette Syndrome was certainly not the cause of any of these issues alone, but it



was a large contributing factor to Paul's discomfort at school. Through a series of searches for the school that would fit my brother, my parents found a boarding school that seemed to provide an answer. Paul's three years there were filled with achievements for our whole family, but there is one that always sticks out for me.

My mom and I got home from school and work one evening, and when she went to listen to the messages on the answering machine, we heard the voice of Quinn, an administrator at Paul's school. What she said next is something I will always remember with a smile. "You would have been so proud of your son today," she said. "He stood up in front of the entire school and gave a ten minute talk and demonstration about Tourette Syndrome." My mother was standing with her hand over her mouth and her eyes wide as can be. Quinn went on. "He was brave and courageous and had all the pride and grace in the world."

You see, Paul had never been able to just have Tourette's at school. He had to hide it, or lie about it, or feel laughed at. We all knew that he was never going to get rid of it, but he had just completely changed his relationship to it. He informed his school about something that he has so that he could be open about it instead of pretending it wasn't there.

I was so inspired by my brother on that day and I am just as inspired today nine years later. I would like to have an ongoing conversation with any youth in Seattle (or anywhere else in the Northwest) to talk about how speaking up and sharing Tourette Syndrome in your school can make it a better place for you, your teachers and fellow students.

Please contact me at: [whatmakesmetic@yahoo.com](mailto:whatmakesmetic@yahoo.com) if you would like to participate in the next meeting for the "What Makes me Tic Project." The next meeting will be in mid or late September.

## MEDICAL NEWS

### Ask the Doctor

#### Vaccinations and Tourette Syndrome – Get Stuck with Evidence

Samuel H. Zinner, M.D.  
Developmental & Behavioral Pediatrician  
University of Washington



**Q:** Do vaccines cause Tourette Syndrome?

**A:** Tourette Syndrome is a diagnosis that is made based on the presence of tics. But Tourette Syndrome is often accompanied by other conditions, including attention difficulties, hyperactivity, learning problems, obsessive thoughts with compulsive behaviors, and even autism. There are many theories about what causes Tourette Syndrome and these related behavioral and developmental conditions, and many people are concerned that vaccines – which are, of course, intended to help their children – may actually be contributing to Tourette Syndrome. Right now, we have no evidence establishing a connection between vaccination and any of these conditions, but we DO have decades of proof that the diseases that kids should be vaccinated against are dangerous and even deadly.

Even though vaccinations have nearly eliminated some very terrible childhood diseases, such as mumps, measles, rubella, and polio, some people now question whether these same vaccines may cause developmental and behavioral problems. In particular, the vaccine for measles has been blamed (mostly for autism, but for other behavioral and developmental problems, too), but many people are concerned about the safety of any and all vaccines.

Much of this current fear about vaccines began in 1998. In that year, a researcher in England and 12 of his co-workers reported in a very important medical journal that they suspected a link between the measles vaccine and autism-like behaviors. This report created an international stir that continues through today, and, as a result, thousands of parents now refuse to vaccinate their children against measles and other childhood illnesses.

The facts, however, do not support the conclusion of the English researcher. Because of the serious concerns of so many people about the safety of vaccines, and the fact that so many parents are now refusing to have their children vaccinated against these very dangerous childhood diseases, there is a huge concern about the possibility of these diseases returning to our children. Measles is a serious illness. The word “measly” comes from measles, and is meant to describe the symptoms of this disease. These symptoms make a person feel lousy, and include fever, diarrhea, cough, rash, runny nose and pink-eye. Unfortunately, for many children, the symptoms can be quite serious, and may also include pneumonia, seizure, brain infection (and

possible permanent developmental disability) and death. Since the 1998 medical report, many unvaccinated children have become sick with measles, and the first reported death to measles in England since 1992 occurred a few months ago.

The vaccine against measles prevents this disease. So, a lot of research in the United States, Europe, and elsewhere, has been done since 1998 to see if these vaccines are causing brain damage (we’ll call this “developmental” problems) or other body organ damage, such as to the stomach and intestines.

In addition to the concerns about the measles vaccine, other vaccines have caused people concern. One of the main concerns about vaccines has centered on the heavy metal mercury, which in some forms, causes damage to the brain. Mercury is contained in a vaccine preservative called thimerosal. The measles vaccine has never contained mercury, but most of the childhood vaccinations once did have thimerosal, although in very small amounts. Although none of the vaccines with thimerosal showed any link to developmental disabilities in children, thimerosal was removed from all routine childhood vaccines over 5 years ago, mostly because of the public’s concern.

So far, good-quality research studies undertaken since the 1998 article was published show us that vaccines are not causing autism and similar developmental and behavioral problems in children. These studies have looked for any relationship between vaccines (both measles vaccine, which contains no mercury, and vaccines that contain thimerosal) and brain or body organ damage. More specifically, in 2004, the Institute of Medicine concluded that there is no association between autism and measles-mumps-rubella vaccine, or vaccines that contain thimerosal as a preservative. In other words, the research evidence indicates that the vaccinations are safe. Known risks to vaccines are rare, and these risks are usually explained to parents and other caregivers at the time the vaccinations are given to the child.

Interestingly, the medical journal that published the 1998 article about a link between the measles vaccine and autism withdrew the article 6 years later, when 10 of the original co-workers said that their study had not been satisfactory to make the conclusions that they made. This was the first time ever in the history of this journal (which is over 100 years old, and is one of the most respected medical journals in the world) that a research article was taken back.

Despite the research evidence, people still worry, so research is ongoing to make sure that vaccines stay safe and are not causing any unreasonable risk to children, including those who have (or who may later have) Tourette Syndrome. While the causes of Tourette Syndrome are unclear, the research evidence shows us that Tourette Syndrome and associated developmental and behavioral conditions are not caused by vaccines. And importantly, vaccines prevent terrible childhood illnesses that were once common, including illnesses that can cause developmental and behavioral problems.

For more information about vaccines and vaccine safety, check out the following information from the Centers for Disease Control and Prevention (CDC), called “Vaccine Beliefs and Concerns” at [www.cdc.gov/node.do/id/0900f3ec80065bff](http://www.cdc.gov/node.do/id/0900f3ec80065bff)

## Washington State Department of Health Begins National Databank Checks of All Health Care Provider License Applicants

By Todd Erik Henry

Private health insurance carriers, HMOs and the health licensing departments of other states have used the National Practitioner Databank and the Health Care Integrity Practitioner Databank in conducting background checks of health care license applicants for years. This databank contains information about applicants from other states. In short, as its name suggests, it is a national databank about health care practitioners. For persons with TS and association conditions, it is important to know that those health care providers, including primary care physicians, neurologists, psychiatrists, psychologists and social workers, have professional histories free from professional misconduct or significant disciplinary action.

The Washington State Department of Health (DOH) will begin to check national databanks when people apply for health care licenses (e.g., medical doctor, RN, LPN, licensed psychologist) in Washington State.

Coupled with state criminal background checks, the additional scrutiny will allow Washington State DOH to look for violations that could affect applicants' ability to deliver safe and quality healthcare.

Use of health care professional databanks allows Washington regulators to review each health license applicant's professional background to see if they have had problems in other states before the state decides whether or not to issue a health profession license, certificate or registration to them to practice in our state.

There has been significant media and legislative attention as well as public concern about the licensing process for some professions in Washington over the past several years. Further, a number of health profession disciplinary cases have attracted attention in the news media.

When multiple databanks are used by a state health profession licensing agency, that agency is able to better access and review possible disciplinary actions against health care providers for conduct relating to their practice. Given the legislature's concern over this issue during the 2006 legislative session, the funds for these new background checks were included in the 2006 - 2007 Washington state budget, signed into law by the governor.

The National Practitioner Databank contains information related to medical, osteopathic, chiropractic and dental practitioners. For persons in the TS community, it is important to know that this is the database where physician information is collected. The National Practitioner Databank includes the following information:

- Medical malpractice payments
- Medicare/Medicaid exclusions
- Actions taken against an applicant's license in other states

- Actions taken against an applicant's clinical privileges and
- Actions taken against an applicant by professional societies.

The other databank that is now being used by Washington DOH is the Health Care Integrity Practitioner Databank. This databank involves any profession regulated by a state and includes such information as:

- Health care-related federal and state civil court judgments
- Health care-related federal and state criminal convictions
- Injunctions
- Federal or state licensing and certification actions
- Exclusions from participation in federal and state health care programs and
- Any other formal actions or decisions defined by government regulation.

While behind the curve, this move forward in Washington State's health profession licensing system will help contribute to patient safety.

## Oregon Task Force Reviews DHS Services

By Todd Erik Henry

The House Interim Task Force on DHS Review is directed to conduct a thorough review of the Oregon Department of Human Services (DHS) to include service delivery, effectiveness of programs, structure, and other related issues. Representative Dennis Richardson is the Task Force Chair.

The Task Force is an open, bi-partisan attempt to evaluate the DHS and provide ideas and suggestions on how to improve the delivery of health and human services in Oregon.

A number of persons with TS and associated conditions receive services from DHS. Oregonians can provide feedback on a variety of topics where DHS is involved, including children's services, the Oregon Health Plan, health services and services for persons with disabilities.

As a person with TS, a parent of a child with TS or as a TS advocate, you may provide feedback to the Task Force by visiting the following website:

[http://www.leg.state.or.us/comm/int\\_comms/dhs\\_review/home.htm](http://www.leg.state.or.us/comm/int_comms/dhs_review/home.htm)

You may also provide comments directly to DHS by directly emailing: [dhs.review@state.or.us](mailto:dhs.review@state.or.us)

I encourage you to visit the Task Force website prior to sending an email to the DHS review email address so that you can make the most productive use of your time, and provide the most useful feedback to DHS.

*Todd Erik Henry, JD, MPA, MA, MS, is Vice President of TSA Washington & Oregon and Board Legislative Liaison. In addition to experience in health insurance administration where he has supervised health care professional credentialing and staff who use health care professional databases, Henry's background includes health policy, and health and human services licensing policy and operations.*

## Support Groups

Please consider helping to start a group in your local area! You will get the help you need to get the group organized and you will be able to access a wealth of TS resources from our chapter and through the National TSA including literature, videos, etc. for your meetings. To make it easier, perhaps team up with another parent to lighten the work load.

Contact Bernadette Witty at (206) 780-5361 or [Bernadette@thewittyfamily.com](mailto:Bernadette@thewittyfamily.com)

### Northend Seattle 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 Avenue N.W.  
Shoreline, WA 98177



### Portland Support Group

**Coordinator:** Erin (503) 293-5050, [tsaoregon@yahoo.com](mailto:tsaoregon@yahoo.com)

**Date & Time:** Sunday Sept 24 3:00 - 4:30  
Sunday Nov 19th 3:00 - 4:30

**Location:** Legacy Good Samaritan Medical Building  
2nd Floor Conference Room  
1040 NW 22nd Ave  
Portland, Oregon



**Directions:** Directly across from Good Samaritan Hospital on 22nd Ave NW between Lovejoy and Marshall Streets. There are 2 parking structures that you can access from Marshall Street just north of the medical building. Enter the front of the building and go up the stairs to the 2nd floor. We are in the conference room on the left.

### Federal Way Support Group

There are no scheduled meetings currently in place for this group. Local contacts in the area are Deb Smith (253) 927-3085 (evenings) and Zita McLaughlin (253) 939-7268.

### Spokane Support Group

There are no scheduled meetings currently in place for this group. A local contact in the area is Mary Ingram (509) 922-0832 or email [tourettesrus@aimcomm.net](mailto:tourettesrus@aimcomm.net)

### Tacoma Support Group

There are no scheduled meetings currently in place for this group. A local contact in the area is Kathy Martin (253) 472-4431 or email [martin4431@msn.com](mailto:martin4431@msn.com)

## Other Resources

**CHADD Support Groups** Children and Adults with Attention Deficit/Hyperactivity Disorder is an all-volunteer organization dedicated to being a resource on such AD/HD issues as school, teachers, children, adults, work, accommodations, diagnosis, resources, family and couples. There are a number of CHADD branches throughout the state. Check out their chapter website for updated listings of CHADD lectures of interest at [www.nwchadd.org](http://www.nwchadd.org).

**ADDResources** A non-profit group established in 1994. AddResources hosts separate monthly support groups for adults with ADHD and for parents of children with ADHD. The meetings are in Seattle and Tacoma and generally have a guest speaker. In addition, ADDResources has a monthly eNews, quarterly newsletter, lending library, and bookstore, and hosts special events, including an annual fall conference. Check them out at [www.addresources.org](http://www.addresources.org)

**PAVE** Parents Are Vital in Education. This is our state's parent information center. It exists for parents of children with disabilities to help them understand the state and federal laws that protect our children. They are an excellent resource for questions having to do with special education in the schools. They have six offices throughout the state. Contact them at 1-(800) 5-PARENT, [wapave9@washingtonpave.com](mailto:wapave9@washingtonpave.com) or [www.washingtonpave.org](http://www.washingtonpave.org) for more information.

## Connections

Tourette Syndrome Association  
122 Bond Road  
Castle Rock, WA 98611

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

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In This Issue...

TS Now Recognized under IDEA - see page 1

## Volunteer Corner



**YADA Days:** We need volunteers to help run the Tourette Syndrome booth at Youth Awareness of Disability Assemblies (YADA) events. YADA is an educational program that involves creating awareness of a wide variety of disabilities, including Tourette Syndrome, among children in elementary schools. Most of the schools so far have been in the Seattle and surrounding areas. Our TS booth aims at helping children understand the symptoms and effects of Tourette Syndrome through a short, interactive talk followed by a fun "Pick-a-Tic" relay game. The kids love the game and learn a lot, so it's actually quite a fun way to spend the day. Volunteers can work for all or part of the two-day event.

**School Advocate:** Be willing to help out parents in IEP meetings or help educate the educators by doing in-service meetings. We would ensure that you get the appropriate required training and you would have direct support from our two certified school advocates in Seattle and Portland.

**Fundraising:** Help plan and implement projects that will raise money to support our chapter's services. We have plenty of ideas for ways to raise money - we just need someone to organize them! You can offer to do just a one-time fundraising event or take on the role for a longer period. Any money we raise helps, so even small projects can be a good place to start. With our connections to all the other TS chapters across the country, it's quite possible that another state has run your fundraising idea, and if so, they would be a great source for information.

**Publicity:** Help promote our chapter and our services through public relations and marketing. This work would include writing press releases, contacting the media and maintaining networks with other organizations affiliated or related to the Tourette Syndrome community. A great opportunity for someone in the Public Relations field.

If you are interested in any of these volunteer opportunities, contact Bernadette Witty at (206) 780-5361 or email [Bernadette@thewittyfamily.com](mailto:Bernadette@thewittyfamily.com)