

Inside TSA

The Quarterly Newsletter of the national Tourette Syndrome Association, Inc.

Summer 2008

Vol. 36 No. 1

GINA Becomes Law

On May 21, 2008, after nearly two decades in Congress, the Genetic Information Nondiscrimination Act (GINA) has finally passed into law with strong bi-partisan support from both the 110th Congress and the White House. The House voted 414-1 for the legislation a week after it passed the Senate on a 95-0 vote. The new law will establish protection against discrimination based on genetic information both in health insurance and employment.

Hailed by Senator Ted Kennedy (D-MA) as “the first Civil-Rights bill of the new Century,” there has never been a federal law protecting individuals from such genetic discrimination. With the passage of GINA, scientific research can further advance while protecting the genetic history of those who undergo tests and clinical trials.

TSA is among a wide range of organizations representing patients, medical professionals, families and employers who campaigned for this fundamental protection. TSA has long and vigorously lobbied on behalf of GINA. During the most recent TSA Trip to the Hill on April 3, 2008, constituents urged their members of Congress to support the procedural motions necessary to ensure the passage of GINA. As a genetic-based disorder, people with TS are immense benefactors from this legislation. Employment hiring, firing and promotion practices and health insurance decisions concerning changes, refusal or conditions of coverage can no longer be based on genetic predispositions, but on performance and functional capacity. TSA is proud of its advocacy in promoting a greater movement towards patient genetic rights and protection.

TSA wishes to thank Congress for working to provide fundamental protections against the misuse of genetic information especially in health insurance coverage and employment situations. TSA also acknowledges the sponsors of the bill, Rep. Louise Slaughter (D-NY) and Rep. Judy Biggert (R-IL), Senators Olympia Snowe (R-ME) and Ted Kennedy, chairman of the Senate Health Committee, for their leadership and tireless efforts on this long standing and critical issue of importance. In addition, TSA expresses its gratitude to the Genetic Alliance Groups for their strong push in advocacy for GINA. ■



TSA's 15th National Conference Brings TSA Members Together

More than 320 people gathered in Alexandria, Virginia for the 15th biannual National TSA Conference from April 1-6. People came from across the U.S. and around the world to learn more about TS, connect with other families and to experience an environment in which TS is the norm and no one ever needs to explain a tic.

Seminars were divided into five distinct tracks: Medical and Behavioral; Education Advocacy; Adult/Young Adult and Teen and Special Topics. A special day long seminar focusing on the needs of the Newly Diagnosed was held as part of the pre-conference offerings, and featured TSA Medical

Advisory Board Chair Dr. John Walkup. Chapter Leadership Trainings, the Youth Ambassador Program and the TSA Annual Trip to the Hill were also part of the pre-conference schedule.

Conference Fun

Highlights included: a fun Meet & Greet Thursday evening with a DJ and Karaoke; a jam session featuring piano jazz master and TSA Board Member Michael Wolff, TSA Board Member and the banquet master of ceremonies Paul Devore on sax, Matt Giordano on drums followed by singer Rick Fowler on guitar; Matt Giordano's drumming circle; a tour of

continued on page 14...

2008 Car Sweepstakes Winner

TSA is happy to congratulate the 2008 Car Sweepstakes Winner, Mary Skaff of Flint, Michigan, the proud owner of a brand new Mercedes C300 Sedan. The next drawing will be on February 23, 2009. For information, contact Susan Cimini in the Development Office at ext. 223.