

## TS PROGRAM GETS MAJOR FEDERAL FUNDING RESULTS OF THREE YEAR EFFORT BY TSA

In 2000, President Clinton signed The Children's Health Act (P.L. 106-310), a large piece of legislation with 36 separate titles creating new programs for various diseases and disorders that affect children, including Tourette Syndrome—a major step forward for TS awareness.

The TS program will be administered by the CDC (Centers for Disease Control & Prevention). It addresses the needs of underserved communities by educating doctors and allied professionals about TS and related disorders and includes a much needed epidemiological study to determine how many people have TS. On January 22, 2004 the bill finally received funding as

part of the Omnibus Appropriations bill with \$1.5 million allocated for the establishment of a public health/research program in fiscal year ending September 30, 2004. There are many reasons it took three years for the legislation to be funded—the economy, Congress's focus on Homeland Security and Iraq, to name a few.

Spending on TS competes with many other worthy causes (like cancer and Alzheimer's research), which impact a much larger percentage of the American people. The inclusion of TS in the roster of the bill's programs is a testament to the persistence of TSA's members and staff, working together to achieve a significant goal.

"I understand that the legislative process can seem complicated and intimidating, but it's my job to help TSA members navigate the murky water and deliver their messages to Congress. I have to give the lion's share of credit for this most recent success to John and Johnny Loder of Florida. The Loders met with their Congressman, C.W. Bill Young, to talk about how the appropriation would help Johnny and others affected by TS. The very personal story of life with TS, which the Loders shared, made the dry text of the law come to life."

— Jeremy Scott  
Director of Public Policy, TSA

## FITNESS AND TS: DOES EXERCISE HELP?



Exercise is good for everyone, but is it especially beneficial for people with Tourette Syndrome? The scientific jury is still out, but the anecdotal evidence is very interesting as many adults and children with TS report that sports and other fitness activities ease tic symptoms.

We did a very unscientific survey of a small group of adults with TS who generously shared their thoughts and opinions about the impact of exercise on TS symptoms. Reasons for working out (from stress reduction to weight control to competitive sports) were as varied as their activities, but everyone in the survey described exercise as a regular part of their lives.

**Reasons to Get Moving** Coach Mark Wootton, a high school football coach and teacher, describes the connection between tics and exercise, "... as much mental as any-

thing." He does weight lifting and cardio workouts to reduce stress and stay in shape. "In the long run, exercise helps me to be less stressed. Less stress reduces the tics."

Puppeteer Kellie Haines runs and cycles all over her hometown of Vancouver—rain or shine. "Exercise has made me strong and confident. Before I have to write a script or do a show that I

am nervous about, I use exercise to calm down and remember what is really important. Exercise clears the cobwebs from my head and makes more room to have fun and not worry so much. TS is a full time job and a part of me that I don't want to get rid of. Exercise is simple. When one has to deal with so many things with TS, it is nice to just allow yourself to run or jump or even sit and do yoga or just breathe."

Dr. Evan Trost, who rides a mountain bike, lifts weights and roller blades, also pointed out that many of the medications used to treat TS can cause weight gain as a side affect. He finds that exercise is a good hedge against this. "In my medical opinion, exercise and nutrition should be at the forefront of any therapeutic regime, provided no contraindications exist."

**Counting Tics** Dr. Trost, like many adults with TS, is very conscious of the waxing and waning of his tics in a given day, as well as over time. He has noted changes before, during and after his workouts. "Especially during weight lifting and in the short time thereafter I have an exacerbation of my tics. I do notice that in the time after exercise—after cooling down—I have a decrease in my tic count as compared to the hours before exercise or similar to

continued on page 8

