

Public Policy Awards, a 50-Visit Trip to the Hill, New Youth Ambassadors at Work and the Champion of Children Congressional Luncheon and Briefing

Congressional Briefing

On March 12, TSA welcomed members of Congress and Congressional staffers to Champion of Children Congressional Luncheon and Briefing in the Rayburn House Office Building. Longtime TSA supporter Chet Edwards (D-Texas) sponsored the room for the luncheon/briefing. It was co-chaired by two members of TSA's Board of Directors: Marcie Kirkpatrick Lipsitz and Randi Zemsky.

The event featured Congresswomen Judy Biggert (R-IL) and Louise McIntosh Slaughter (D-NY) accepting the TSA 2009 Public Policy Awards for their work on the Genetic Information Nondiscrimination Act (GINA). They each spoke about the passage of this critical piece of legislation.

In her remarks, TSA President Judit Ungar promoted the important 'Dear Colleague Letter' supporting continued funding for the TSA/CDC Program Partnership.

"I am happy to tell you that this year's Dear Colleague Letter in support of continuing our critical programs is circulating and I hope that all of you will sign on. It is terribly important for the people with TS that this partnership with the CDC be funded in fiscal year 2010 as it has been for the past five years. For the many thousands of families whose

young children will be diagnosed in the years to come, this program is essential," Judit said.

Judit singled out some of TSA's Champions in Congress including C.W. Bill Young, Carolyn McCarthy, Pete Sessions and Chet Edwards. She also praised the TSA Youth Ambassadors who spoke at the briefing and mingled with the representatives and staffers after the formal speeches.

Youth Ambassadors Speak at Briefing

In addition to the founder of the TSA Youth Ambassador Program, Jen Zwilling, three newly trained Youth Ambassadors: Ariel Small, Isabella Constantino and Hunter Lindberg spoke at the Congressional Briefing. Hunter was particularly eloquent on the subject of spreading awareness among educators about TS.

"It feels cliché to say that education and awareness make a difference. But having been punished for having the tics of Tourette Syndrome, punished as if I had a behavioral problem, I know first-hand the dramatic difference that education and awareness can make for a kid with TS. Last year, I was fortunate to be in the first national group of Youth Ambassadors. I started in my own school, but I have traveled all around Tennessee advocating for kids who had trouble like I had. Prior to starting the YA program, one teacher always sat me in the corner away from

everyone else when I had bad tic days. I was determined to enlighten him about TS. After educating the faculty at an in-service, the teacher responded by giving me a stress relief ball and nothing but support from that point on," Hunter stated.

The newly-trained Youth Ambassadors had been briefed the night before the luncheon by Elridge Proctor and John K. Yi of the TSA Public Policy Office, as part of their intensive YA training (see page 10) and were ready to speak from the heart to an audience that could be jaded by repeated appeals from worthy causes. Ariel painted a vivid picture of the obstacles he faces at school and Isabella spoke of the response she received to appearing in the ABC *Primetime* Special about TS. Their youthful contributions to the event helped raise awareness by putting a human face on the pages of legislation.

Trip the Hill by Youth Ambassadors and More

After the Congressional Luncheon, the TSA Public Policy Office organized over 50 visits to the offices of representatives with TSA staffers, Youth Ambassadors and Government Relations Chapter Liaisons promoting the importance of the TSA/CDC Program Partnership and spreading general awareness of TS. By combining the TSA staff and Youth Ambassadors

with government relations professionals, this extraordinary number of meetings was made possible. Elridge Proctor, VP of TSA Government Relations, said, "This dual approach can only strengthen our message, not hurt our cause, if we can coordinate our meetings into a strategic approach to further influence Congressional Offices."

One of the new Youth Ambassadors, Zach Pezzillo of Hawaii, expressed his excitement at the opportunity to meet with his state's representatives. "Meeting with our Hawaii representatives was a great experience. They were both very interested in what I had to say and I learned a lot about lobbying. It was enlightening and empowering to know that I got to be part of our legislative process in a way that would help kids with Tourette Syndrome," Zach said.

The TSA Youth Ambassadors returned to their home communities with the knowledge and confidence to advocate for themselves and other young people. They also have first-hand experience in the workings of democracy. TSA is dedicated to the continuing growth of the Youth Ambassador program.

"We believe that by empowering individual young people, we will shape a future that is better for everyone who copes with TS and other challenges," Judit Ungar concluded. ●