



# NJ Center for Tourette Syndrome

AND ASSOCIATED DISORDERS, INC.

*Collaborative Partnerships for the Tourette Syndrome Community*

## According to the CDC: 1 in 100 children exhibit symptoms of TS

### Tourette Syndrome Quick Facts

**Tourette Syndrome (TS) – An inherited neurological disorder characterized by the childhood onset of uncontrollable vocal and physical tics.**

Tics can include head jerking, eye blinking, facial grimaces, jumping, spinning, sniffing, throat clearing, squealing, barking and more. Vocal tics can include echolalia, involuntary repetition of what someone else has just said, the involuntary repetition of one's own words and the most infamous and problematic vocal tic: coprolalia, which is the involuntary utterance of curse words, ethnic or racial slurs (fewer than 15 percent display these symptoms).

- Usually appears when a child is 6 or 7 years old
- Affects every race and ethnic group
- Boys affected 3-5 times more often than girls
- Lifelong condition – cause unknown – no cure
- No standard treatment protocol
- Average time from onset to diagnosis more than 7 years
- Psychological, social, educational, physical impact to individual
- 86% of children living with TS have also been diagnosed with a associated disorders such as ADHD, OCD, Anxiety Disorders, and Learning Disabilities.

### Tourette Syndrome is ...

- Under-represented in medical texts
- Misunderstood by the public and professionals
- Underdiagnosed by the medical community
- Misrepresented by the media
- Misunderstood by educators
- Spectrum disorder – severe to mild

**“Improvements in TS diagnosis and treatment can be advanced by educating medical and allied professionals, and educators.”**

– Centers for Disease Control

**NJCTS provides direct services and referrals for families, training of the next generation of qualified professionals, and support for research that will lead to better treatments and a cure.**

## Services available:

- **Referrals for medical diagnosis and treatment**
- **Referrals for psychological services**
- **Coordinated family support** among partner and community organizations throughout the state
- **Education outreach** including faculty trainings, peer presentations, and workshops designed to empower students and prepare teachers and administrators to best accommodate students with TS and associated disorders
- **Medical outreach** at hospitals and medical schools statewide to develop a new generation of doctors, physicians and other medical professionals who are knowledgeable about TS and associated disorders
- **Research into causes** and effective treatments for TS and associated disorders
- **The nation's only university-based, standalone student clinician TS clinic**, located at Rutgers University
- **The world's first TS cell and DNA sharing repository**, making genetic material available to qualified researchers worldwide looking for treatments and a cure
- **Federal legislation** to provide services and research opportunities that will ultimately assist individuals with TS and associated disorders

## NJCTS is the nation's first Center of Excellence for families, medical, and education professionals dealing with TS

- **Family Outreach**
  - Support Groups
  - Medical/mental health referrals
  - Advocacy Training
- **Medical Outreach:**
  - Patient-Centered Medical Education
  - TS Clinic at the Graduate School of Applied and Professional Psychology at Rutgers University
  - Grand round at hospitals statewide
- **Education Outreach**
  - Educator In-Service Program
  - Peer/Student-Led In-Service Program
  - Professional Conferences
- **Research**
  - NJCTS Cell and DNA Sharing Repository at Rutgers University
  - TS Clinic at the Graduate School of Applied and Professional Psychology at Rutgers University
- **Advocacy**
  - Anti-Stigma Campaign
  - *NJ Walks for TS* Program
  - Landmark state and federal legislation for the TS Community



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