



New Jersey Center for Tourette Syndrome  
AND ASSOCIATED DISORDERS

*Collaborative Partnerships  
for the Tourette Syndrome Community*

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## **“Approaching Tourette Syndrome” article in Chinese publication describes Camp Bernie experience**

*The New Jersey Center for Tourette Syndrome held its 9<sup>th</sup> annual Family Retreat Weekend on June 7-9, and Chinese reporter Lichun Zhang was there to chronicle it*

LEBANON TOWNSHIP, N.J. – *The following story was written (originally in Chinese and translated here into English) for the New Jersey Center for Tourette Syndrome & Associated Disorders (NJCTS) by Lichun Zhang and appeared June 28 in an all-Chinese publication online and in print:*

Tourette Syndrome, also known as multiple tics-coprolalia syndrome, refers to involuntary and sudden multiple tics and twitching, accompanied by the outbreak of vocal and Tourette tic disorders. Currently, Tourette Syndrome and autism incidence is almost the same, and although Tourette Syndrome has drawn mainstream attention and launched a wealth of research, Asian-Chinese groups know very little about it.

### **Understand Tourette Syndrome**

It is understood that Tourette Syndrome pathogenesis is related to genetic factors, neurotransmitter imbalance, psychological, environmental and a variety of other factors, and may be a result of interactions between these factors during development. Onset is mainly between 2 to 15 years old, more in males than in females.

The symptoms are often intermittent, sometimes more severe and other times less severe. The symptoms increase when stressed, anxious, fatigued or lack of sleep; reduce when relaxed; and can disappear when asleep. Patients often have normal IQ. Some children have problems with attention, learning difficulties, mood disorders and other psychological problems, sometimes



Photo by Cynthia Liang

**Parent-child communication activities made parents very pleased at the 9<sup>th</sup> annual New Jersey Center for Tourette Syndrome & Associated Disorders Family Retreat Weekend at Camp Bernie.**

complicated with obsessive-compulsive disorder, attention deficit hyperactivity disorder and other disorders. First reported by the French physician Gilles de la Tourette, as early as 1885, the pathogenesis of Tourette Syndrome is not well understood due to the complexity of the disease and the limitation of research.

Unlike autism and depression, Tourette Syndrome does not get the appropriate amount of attention. When in school, children are sometimes bullied, and teachers may not be aware of the disease and consider it as "bad behavior." The kids may get punished and ridiculed by classmates, which affects learning and even causes psychological problems. The incidence of the disease in the world is as high as 0.3 percent to 1 percent, and for children between 5-18 years old, the incidence goes up – 0.5 percent to 4 percent, which is almost as high as the more familiar "autism."

### **Mainstream attention on Tourette Syndrome**

Tourette Syndrome is increasingly valued by mainstream society. The New Jersey Center for Tourette Syndrome (NJCTS) is a nonprofit organization established in 2003. The organization's work includes training of teachers in schools and doctors in hospitals to introduce onset of symptoms, contact the sick child's parents, help the families of patients and medical institutions to deal with the disease, and so on.

The organization has organized parent-child camping activities for nine consecutive years, inviting Tourette Syndrome children and parents in New Jersey and surrounding areas. They also invite relevant medical, educational and research institutions to create the platform for communication.

Camp Bernie holds the three-day-camp every year for the New Jersey Center for Tourette Syndrome, which invites those who have been diagnosed with Tourette Syndrome, as well as related symptoms, to participate in the annual activities. About 200 people come to the camp.

Through this event, children, parents, doctors, teachers and researchers spend three days of living together so that children can understand each other and parents can also share and exchange ideas about treatment and educational experiences. After participating in three days of camping activities, some parents were emotionally in tears and said that through such camping activities, communicating with parents and children sharing the same experience, they got great spiritual consolation.

### **Rutgers Human Genetics Institute put focus on Tourette Syndrome**

To help NJCTS study this disease, the Human Genetics Institute at Rutgers University has been involved in Tourette Syndrome research for many years. Dr. Jay Tischfield is the director of Human Genetics Institute and CEO of the Rutgers University Cell and DNA Repository (RUCDR). He founded RUCDR 15 years ago, and RUCDR has developed from a dozen people to 120 employees and become the world's largest university-based biorepository.

RUCDR also participates in a number of national neurological and psychiatric disorders research projects, including autism, schizophrenia and alcohol abuse. Recently, RUCDR completed an \$11.8 million renovation project to create a new Genomics Technology Center. The center was built with a full set of advanced equipment, including cutting-edge automated machines for extraction of DNA and RNA, and next-generation sequencing instruments that meet the criteria for a CLIA laboratory.

Research on Tourette Syndrome includes processing blood cells and differentiating them into stem cells and nerve cells. This can be used as a model to study the difference between affected and nonaffected neuron cells. Dr. Tischfield said, "If the disease genes relate with certain metabolic pathways, you can try using the relevant medication. For the two known genes of Tourette Syndrome, drug research has come to the clinical trial stage."

### **Chinese families holds evasive attitude for Tourette Syndrome**

Studies have shown that the incidence of Tourette Syndrome and autism is now the same, but in Chinese families, Tourette Syndrome is not a familiar concept. Some families have the so-called "bad boy" or "ADHD" children who may have Tourette Syndrome. In many cases, this leads to the absence of further treatment or delay of the best time for treatment.

At Rutgers, there are some Chinese researchers involved in the study of Tourette Syndrome. Li Deng is one of them, and she attended this year's camping activities. She said that Chinese families have very limited knowledge and acceptance of treatment for Tourette Syndrome. On one hand, this is caused by lack of knowledge of relevant research institutions, nonprofit organizations and procedures to join the United States research activities and programs.

Li Deng told a story about a Chinese Tourette Syndrome family who participated in the camp activities. After the event, feeling deeply touched, she said, "In this environment, I can finally breathe freely." Li Deng also suggested that some Chinese families, based on the traditional Chinese good-face attitude, are unwilling to admit their child has Tourette Syndrome. They suffer in silence and do not go to a doctor. Li hopes Chinese families will correctly treat Tourette Syndrome – paying attention to a child's abnormal behavior, as Tourette Syndrome can interfere with a child's cognitive function and development, affecting their ability to adapt to society.

Meanwhile, the family atmosphere and the attitude of parents on the child's condition have a very big impact. She also said: "If there is a need for help, Chinese families can contact me through the Rutgers University Human Genetics Institute for assistance. This will not only help children for treatment of Tourette Syndrome, but also help the research on Tourette Syndrome, which will benefit more families and children with similar experience in the future."

*June 6-8, 2014, will mark the 10<sup>th</sup> anniversary of the Family Retreat Weekend, and it once again is scheduled to take place at YMCA Camp Bernie. For more information about the Family Retreat Weekend, please call NJCTS at 908-575-7350 or visit [www.njcts.org](http://www.njcts.org).*

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*New Jersey Center for Tourette Syndrome and Associated Disorders, Inc.  
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