Ask The

MEDICAL ADVISORY BOARD

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What kinds of association(s) exist between tics and allergies?

Both tics and allergies are relatively common among young children. Some signs of allergy might be confused with the symptoms of TS. In one study, the prevalence of allergy in TS patients was found to be higher than the general population. However, information about an association of TS with allergies is scant and not conclusive. Allergists should be aware of the symptoms of TS because TS patients may be referred to them before there has been a confirmed diagnosis of TS.

It is important to note that there is also an association between tic exacerbation and the use of medications used to treat allergies. I have found that at times tics may worsen when taking certain allergy medications. This observation is based on the experience of doctors who treat tics, and has not been systematically studied. Therefore, we all should be aware of this possibility, and be sure to monitor tic severity closely with the help of our physicians when such medications are taken.

I have been diagnosed with TS for many years. I tried many medications that didn't work. Recently, I heard about a new medication, named Dronabinol (Marinol). Is this medication an effective treatment for Tourette syndrome?

Dronabinol, the active ingredient in Marinol, is synthetic delta-9-tetrahydrocannabinol (delta-9-THC). This substance is also a naturally occurring component of marijuana. Marinol is used as an appetite stimulant in the treatment of AIDS-related anorexia and for the treatment of nausea and vomiting in chemotherapy patients. Anecdotal reports, a retrospective survey and a pilot study have suggested a beneficial influence of smoking marijuana on tics and associated behavioral disorders in TS. Most of the reported findings are very preliminary, and need to be confirmed in a much larger and more rigorously designed study. Additionally, this substance is addictive and we suspect that its chronic use causes cognitive impairment, and may be harmful to executive functions and cause selective short-term memory deficits. Therefore, based on the limited, existing evidence, the use of Marinol as a tic treatment is not recommended.

My son is five years old. He has had both facial and motor tics since he was three. My pediatrician says not to worry because his tics will disappear as he gets older. I am worried. Everything I have read suggests that he is too young to have these symptoms. Is it possible for him to have been diagnosed at age three? Should I see a neurologist for a second opinion?

In most cases, the onset of tics occurs between 2 and 15 years of age, with the mean age of onset being seven. Therefore, although more often the symptoms start later, it is not unusual for onset to begin at three. The initial tics usually occur in the upper body, commonly involving the eyes (e.g. blinking) or other parts of the face. Vocal tics usually develop afterward-even one to two years later. Typically, the tics wax and wane with a changing repertoire over time. For the majority of individuals, the period of the worst tics usually occurs between the ages of 7 and 15, and then often there is a steady decline in symptoms. During late adolescence and early adulthood symptoms stabilize, i.e. fewer varieties of tics appear and they are, in many cases, milder. Complete remission of both motor and vocal tics has been reported. However, estimates vary considerably, with some studies reporting rates of remission as high as 50%. Tic disorders and Tourette syndrome are conditions that may require specialized care. Even when specific treatment is not needed, a specialist can confirm the diagnosis and provide the needed education.

My son has been taking Prozac for TS for several months. He seems to be getting worse. I would like to know whether this medication is an effective treatment for TS? Are there side effects to this medication that I should know about?

In many instances, the tics of TS are associated with symptoms and signs of obsessive-compulsive disorder (OCD) as well as those of attention deficit hyperactivity disorder (ADHD). Actually, symptoms of OCD may prove even more disabling than motor and vocal tics for some patients. They may result in impaired school or job performance and disrupt family or social life.

When approaching a child or adult with TS, one has to determine which symptom is more disabling. There are different treatments for tics, OCD and ADHD. The tics respond to treatment with medications that block dopamine. Medications inhibiting the uptake of serotonin, such as Prozac, Zoloft or Paxil, can reduce the obsessions and compulsions associated with OCD. Clinical response to Prozac may be delayed by several weeks, and it appears to cause fewer and less toxic side effects than the older antidepressants. Possible side effects of Prozac include stomach upset, nausea, loss of appetite, skin rash, insomnia, hypomanic behavior (feeling wired up), tremor, and loss of libido. Some TS patients have reported a reduction of tics, and some parents have reported improvement in their child's school performance when taking Prozac. However, these effects have not been formally assessed.

If your child has been on Prozac for several months and "is getting worse," this is not necessarily related to the medication. It may be that the condition is getting worse because of its waxing and waning nature. You should consult with your doctor about which symptoms were targeted specifically with this medication. Often, more than one medication has to be tried before we find the one that works for the specific situation.

Most of my family has been diagnosed with OCD. Recently, my son was diagnosed with TS. However, many of the symptoms he displays resemble those of certain family members who have been diagnosed with OCD. What is the difference between TS and OCD, and what are the symptoms?

TS is a disorder that starts in childhood and is characterized by tics that wax and wane and change over time. OCD is characterized by persistent obsessions (recurrent, intrusive thoughts, most of the time

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Ask The MAB (continued)

uncomfortable) or compulsions (repetitive behaviors performed according to certain rules or in a stereotyped fashion). These symptoms are a significant source of distress for the individual and tend to interfere with his ability to function socially, academically, or professionally. There is a genetic association between TS and OCD. That is, there are families where a genetic susceptibility is expressed in some members as tics and in other members as OCD behaviors or both.

The complex motor tics of TS may be difficult to distinguish from compulsions. Some report that tics are preceded by premonitory sensory symptoms or an urge, and once exposed are followed by relief. Tics are to a certain degree suppressible. In contrast to tics, compulsions are performed in response to an obsession, according to certain rules (e.g., a certain number of times or at a particular time of the day) or rituals, and thought by the person to prevent either discomfort or a dreaded event. The compulsion is not necessarily connected realistically with what it is thought to prevent, and the individual is quite aware that it is excessive or unreasonable. In contrast to tics, the performance of the compulsive act is usually neither satisfying nor pleasurable.

Obsessions in TS are different in nature than the obsessions seen in full blown OCD without TS. Those with TS seem more likely to have obsessions associated with sexual, aggressive, or religious themes. The compulsions commonly found in people with TS include checking, ordering, counting, repeating, forced touching, self-injury, symmetry, evening up, and repetition until something feels "just right". Obsessions and compulsions seen in people with OCD who do not have TS are commonly associated with fear of bugs, fear of something going wrong or someone becoming ill, as well as excessive cleaning and washing rituals.

The distinction between compulsions and complex tics is not always possible to make, and occasionally a doctor has to rely on the response to different therapeutic manipulations. Complex and simple tics respond to drugs that block the neurotransmitter dopamine, such as Orap, Haldol, Risperdal, Zyprexa, or Seroquel, while OCD symptoms are reduced by medications that act on serotonin, like Prozac, Zoloft, Paxil.

The TSA Philosophy: Don't Follow Legislation, Shape It!

by **Jeremy Scott, Government Relations Specialist**

The introduction of new legislation can have a major impact on you and your family and your participation is crucial. This is why the Tourette Syndrome Association is pleased to introduce a new resource available online to its members—public policy information.

A recent Pew Internet and American Life Project study shows more Americans are going online, actively contacting their elected officials and seeking out government information, and TSA is a part of this growing trend. To help members become more personally involved in the political process, TSA has included on its Web site all the necessary tools and information to communicate effectively with your federally elected officials.

TSA's Public Policy section includes:

— Government Relations Committee and Advocacy Statement
— TSA legislative priorities
— TSA position statements
— TSA advocacy statements
— Current legislation that affects TS
— Issue action alerts, where members can take action
— Congressional links

These tools enable members to educate themselves on issues important to TS; identify their federally elected Senators and Representatives; and communicate their views to their lawmakers.

Please check the Web site frequently for updates and requests on how we can all work together to influence public policy.

Two New Laws Include Tourette Syndrome

On November 6, 2002 President Bush signed into law "The Rare Diseases Act of 2002" (H.R. 4013) and "The Rare Diseases Orphan Product Development Act of 2002" (H.R. 4014). These two pieces of legislation are intended to spur development of drugs to treat rare diseases. Tourette Syndrome was among the 6,000 rare diseases (defined as medical conditions affecting fewer that 200,000 people) mentioned in both pieces of legislation.

In 1993, Congress established the Office of Rare Diseases (ORD) within the National Institutes of Health (NIH) to promote research and collaboration on rare diseases, but it never received its own budget. Now, H.R. 4013 provides the ORD with an annual authorizing budget of $4 million through 2006 and has an increasingly important role in formulating the research agenda at the NIH. The law also authorizes $20 million annually through 2006 for cooperative agreements and grants to Rare Diseases Regional Centers of Excellence.

H.R. 4014 will double the current authorizing funding level for the Food and Drug Administration (FDA) Orphan Products Research Grant Program from $12 million to $25 million annually, thus enabling the development of many new treatments for rare diseases in the future.

There is still much that needs to be done. These two laws only authorize increased funding at both the NIH and FDA. Next year, we need all of you to continue to reach out to your Senators and Representatives to ensure that both pieces of legislation are fully funded.

Fran Zigman Honored at TSA Friars Club Benefit

In honor of her long-time commitment to TSA, Fran Zigman receives testimonial plaque from Mark Levine, TSA's VP, Development. The event was a surprise birthday party roast at the Friars Club in Beverly Hills, California given by her husband, Lou. All proceeds went to TSA.