

In each issue, a member of TSA's Medical Advisory Board addresses medical questions that affect people with TS and their families. This issue's contributor is Gerald Erenberg, M.D., Pediatric Neurologist, Cleveland, OH and Chairman of the TSA Medical Advisory Board.



Q As a child I was diagnosed with both TS and diabetes. When I attended summer camps for kids with diabetes, I was surprised to find many others who had TS too. Is it common to have both conditions?

A Actually, it is uncommon to have both diabetes and TS. None of the 1100 patients with TS in our clinic also have diabetes. Although there is no reason why the two could not exist in the same person, the two conditions are not medically associated. I believe that your experience was simply a coincidence.

Q I find that certain clothes make me feel uncomfortable to the point where I cannot tolerate wearing them. Is this symptomatic of TS or an indication of another condition?

A Finding certain clothes uncomfortable is a common complaint of people with TS. While not due to a tic, it is part of the spectrum of associated conditions that are so frequently part of TS. This is usually looked upon as an obsessive-compulsive behavior in which things need to "feel just right."

Q As a teenager, my tics seemed to decrease when I smoked marijuana. I stopped using marijuana years ago but I've recently read on the Internet that a pharmaceutical form of marijuana can be beneficial in reducing tics. Is there any credible research on the effect of marijuana on TS tics?

A One of the active ingredients in marijuana is known to have an effect on the dopamine cells in the brain. Since the neurotransmitter known as dopamine is involved in TS, it has occurred to neuroscientists that there might be some effect of marijuana products on dopamine and thus on TS. Research into the potential benefit of the active ingredients in marijuana is going on at this time. One such study is being funded by TSA. Only time will tell whether there will be any benefit found from the use of some of these active ingredients.

Q Are there any food groups that a person with TS should avoid?

A Although there is universal agreement that eating properly is essential to good health, there have been ongoing debates on whether specific foods or food groups might contribute to a worsening of disorders such as TS. Some physicians believe that TS symptom expressions might be due to an allergic reaction to specific foods. This kind of reaction would be unique for each individual. Others have argued that there are additives and artificial ingredients in foods that can trigger the development of TS in anyone exposed to them. It would follow that such artificial ingredients should be avoided.

The idea of eliminating certain foods, or food groups, from one's diet remains controversial as does the belief that dietary and other supplements (i.e. mixtures of vitamins, minerals, herbs and enzymes) can be used as effective treatments for TS symptoms. While others may disagree, it is my personal opinion that none of these supplements can be recommended currently because of the lack of any scientific evidence of their efficacy.

Update: TS Genetics Research

Most Newsletter readers know by now that exciting data have emerged from the work of the TSA-funded International Consortium for TS Genetics. This collaborative group consisting of ten research centers from six countries is unique in the community of genetic research. With the support of the TSA, members have been cooperating closely on this effort for over a decade.

Recently, this group has authored a scientific article* describing its investigation carried out on 100 sibling pairs clearly affected by TS. The work involved the completion of the first scan of the human genome, and based on these analyses, it has successfully identified several chromosomal regions that are believed to be potential sites for the genes that cause TS.

In order to strengthen these findings, it is now imperative that the Consortium quickly interview and study 200 additional pairs of siblings with TS. Please read the accompanying call for family participation to see whether your family might be appropriate for this study. If you believe your family fits the description, PLEASE write to TSA/Attention: Genetic Research so that an investigator can call you directly to describe the study in more detail.

* Readers wishing a copy of the Consortium's article from the November issue of the *American Journal of Human Genetics*, can obtain one by writing to the TSA. Please include \$5.00 to cover printing and S&H.

Affected Siblings Urgently Needed for Genetics Study

Families appropriate for this study are those who:

1. Have two or more clearly affected siblings;
2. Have biological parents available for participation;
3. Are willing to provide blood samples and to be interviewed by a genetic researcher.

If you believe your family fits these criteria, and are willing to be called by an investigator for a preliminary interview, please write to TSA/Attention: Genetic Research.

If you take Orap (pimozide), this information is for you . . .

1. Beginning in the Fall, GATE pharmaceuticals began making Orap available in pills of 1 mg strength.
2. A general notice from the manufacturer to physicians warns that the following medications should NOT be taken in conjunction with Orap:
 - . . Macrolide antibiotics (e.g. clarithromycin, erythromycin, dirithromycin, troleandomycin)
 - . . Azole antifungal agents (e.g. itraconazole, ketoconazole)
 - . . Protease inhibitors (e.g. ritonavir, saquinavir, indinavir, nelfinavir)
 - . . Nefazodone
 - . . Zileuton

As a precaution, patients should also avoid grapefruit juice because it contains substances that may inhibit the metabolism of pimozide by CYP 3A.

If you have questions about about this information, we urge you to contact your personal physician.