

## ASK THE MEDICAL ADVISORY BOARD

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 Cathy Budman, M.D., Director of Movement Disorder Center, Department of Psychology and Neurology, Manhasset, NY.



**Q** How can I enlist my doctor to advocate on my behalf in other areas, e.g. at school, work, etc.?

**A** Ideally, all physicians treating people with TS should act as strong advocates for their patients. Unfortunately, many find themselves unable to spend the extensive time required to do this. For busy physicians, it helps when patients draft the necessary letters including the names and addresses of those to be contacted. (Many of my patients have become very well versed in necessary school modifications, and they prepare letters which I edit and then mail.) Likewise, it can be helpful to prepare similar drafts to insurance companies. Include basic information such as date of birth, social security number, etc. This helps you enlist your doctor's support and timely response. (*Sample letters are available through national TSA.*)

**Q** How best can we advocate for ourselves with our doctors?

**A** It is my feeling that if you find yourself in a situation where you genuinely believe your doctor is unwilling to listen or take your concerns seriously, it may be necessary to find a different doctor. A good match between patient and physician is very important, but these days many do not have the luxury of choosing their physicians. If you are in such a bind, try to prepare well before each visit, and be firm (not confrontational) about getting all of your questions answered before the visit is over. Request another visit when you feel that you have not had your concerns adequately addressed. Do not be afraid to raise the possibility of seeking a second opinion. While some physicians may feel offended, most will feel relieved that you are seeking a second opinion from a specialist—particularly in complex cases where treatment may require multiple approaches, e.g. medication, school intervention and/or behavioral therapy.

**Q** What do you think about taking notes or tape recording visits to my doctor?

**A** I am a strong believer in an educated consumer. Therefore, I like to see patients make every effort to learn as much as they can. I tell my patients to keep a notebook to record questions prior to, and during, each visit. Also, they should keep a log of medication used that include dates and dosages, as well as experienced side-effects if possible. I also suggest keeping one folder for school-related information, and another for copies of all previous medical evaluation reports.

Using a tape recorder is helpful because information from the visit can be reviewed afterwards. However, some physicians may feel put off by being recorded and this reaction may serve to undermine the good physician/patient relationship so necessary to quality care. It may be less intimidating to record notes while you are with your doctor. If you really need to tape, be sure to ask your doctor beforehand whether you may record the visit. I wouldn't insist if a physician is opposed to the idea of taping.

## CNS Spectrum Focuses on TS

*CNS Spectrum*, a respected and widely read neuropsychiatric journal with a circulation of 42,000, will devote two issues to Tourette Syndrome. This monthly publication focuses on the direct relationship between the findings of basic scientific research and neurobiological disorders with behavioral manifestations.

By choosing to devote two issues (January & February 1999) to TS, Eric Hollander, M.D., the editor of *CNS Spectrum*, is attesting to the explosion of recent findings in TS-related research. Neal Swerdlow, M.D., Ph.D., the chair of TSA's Scientific Advisory Board, and Gerald Erenberg, M.D., chair of TSA Medical Advisory Board, have volunteered their time and expertise as guest editors.

TSA will have copies of these issues on hand for interested professionals. Please send \$3 to cover shipping and handling, and address your request to Sue Levi-Pearl at national TSA.

## Attention: Researchers and Physicians

TSA is sponsoring the 3rd International Scientific Symposium on Tourette Syndrome, New York City, June 4-6, 1999. The conference will focus on new findings in basic science and recent studies in clinical phenomenology. For information on attending the symposium, scientists should contact national TSA.

## Families Needed for Genetic Research

TSA-funded researchers are seeking families for genetic studies. Needed are two or more siblings or cousins from the same family that have a confirmed TS diagnosis. If your family fits this profile and you are willing to be called by a researcher, please write to TSA, Att: Genetic Research.

## 2nd Annual West Coast Awards Dinner Held



On February 4, 1999, the 2nd Annual West Coast Awards Dinner was held at the Regent Beverly Wilshire Hotel in California. Pictured are our Honorees, Cuba Gooding, Jr. (left) and Maury Povich.