



REAL LIFE STORIES: GRANDPARENTS OF CHILDREN WITH TS

It is often said that grandparents get to spoil their grandchildren, unlike parents who must provide discipline as well as love. But grandparenting can be so much more. Grandparents can be mentors, role models, confidants, friends and provide unique links to family traditions and history. They can help celebrate big and small milestones while helping children see the "big picture" from the perspective of experience.

Children with TS, who may have a hard time at school, feel the sting of competition with their siblings or wonder why they've been singled out for a mysterious neurological disorder, benefit from that extra dose of unconditional love that only grandparents can provide. One-on-one time with a grandparent—on a special excursion or just over ice cream—can give children with TS the opportunity to talk candidly about their feelings, or just enjoy time when no one is concerned about the tics that strangers may find distracting.

Barbara, Jesse and Jordan

Barbara Shefsky has two grandsons with TS—Jesse and Jordan. She describes her daughter Kathy, the boys' mother, as being "very astute" in diagnosing her sons' TS. Kathy has also been dogged in her pursuit of the scholastic accommodations that both boys need to stay in their local public schools. Barbara and her husband sought out the late Dr. Donald Cohen who was very helpful in guiding the family's education about TS. The boys are now fifteen and twelve. With their parents in solid control of the medical and educational aspects of the boys' lives, Barbara gets to play the role of fun grandma.

"I see them as often as I can. I live in the City (New York) and the boys live in New Rochelle. We're good friends. When they were younger I would treat them to Broadway shows—like the Lion King. Now the biggest treat is going out to dinner. They like a Japanese restaurant where

you cook your own dinner at the table. They are both very affectionate kids and close to their cousin who is sixteen. She has a learning disability and they are patient and understanding with her—and she is with them."

Barbara recently received a wonderful compliment from Jesse who asked her to take him on a clothes shopping expedition for his birthday. "He didn't just want the money. He wanted to go together." But Barbara is "cooler" than the average grandmother. She often listens to rap music with the boys when they're in the car. "I like some of it. I don't like the tough lyrics, but the kids know the words."

She believes that the genetic link to TS is the family of her deceased first husband. In her immediate family it has always been a topic open for discussion, but members of the extended clan have responded with varied degrees of candor. She recalled an incident involving the young son of a cousin.

"A year or two ago, one of my cousins, had been away in England for a year with her five or six year-old-son. The boy came back with all kinds of tics. My side of the family all thought it was TS. I invited my cousin and her husband to dinner and told her. It looks like your grandson has TS, maybe I'm supersensitive, but it looks that way. Her husband denied it completely, but she said maybe. The same cousin had a son who had a tic as a young boy, a tic that he outgrew."

"There seems to be a thread running through my late husband's side of the family. It was interesting that nobody discussed it with us (my daughter and I) knowing about our involvement with TSA. But I'm pretty loose about it, because of how I felt when I lost my husband to cancer. In the beginning I was in denial. It's a little embarrassing, that feeling of contagiousness. I tried to keep it low key, but as he got sicker and sicker I realized that I needed help, support and knowledge. That's what happened with TS. I needed

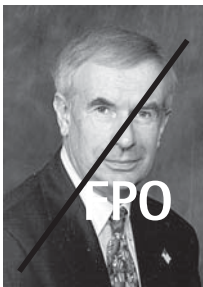
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Barbara, Jesse and Jordan



From The Chairman



Fred Cook

Needed: Backbones

When I was in high school and I wasn't particularly motivated to work hard, a teacher I admired told me that there were three bones a person could be, and that I needed to choose one for myself. The first bone—or kind of person—was a jawbone, who is always talking about what should be done, but never takes any action. The second kind of bone was the wishbone. You can imagine that a person who is a wishbone is always hoping to change a situation, but also takes no action. The third bone is the backbone. Backbones are the people who take responsibility and act. They take the ideas that the jawbones

talk about and the wishes that the wish bones imagine and they change reality by acting—regardless of the obstacles.

Now, so many years later, I'm looking at people with a different twist. I think we need to be all three bones at once. We need to be jawbones and talk about TS and TSA. We need to get the word out and be vocal. We also need to talk about our ideas as a one step toward making them happen. We also need to be wishbones. Because wishbones are the people who can imagine great things—cures, treatments, scientific discoveries. But most of all we have to be backbones. We have to put the ideas and wishes into action.

As the chairman of TSA I'm recruiting people with all three bones. Get involved. Talk, wish and do, together we can overcome any obstacle.

From The President

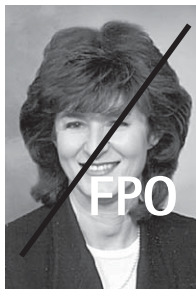
Grandparents – Special People

When I think about the significant people in my life I cannot help but remember my grandmother and grandfather. We lived with my grandparents until I was twelve years old and they were a very important part of my early years. What I remember the most is the unconditional love they gave me. Everything I did was wonderful. I could do no wrong. I never had to finish my food or eat anything I didn't like. We used to go on adventures together—mountain climbing, the farmer's market to buy fresh vegetables and live fish, vacations at the Lake front, or just sit together quietly and read a book or listen to the radio.

My grandparents were very special people, and sometimes I think that was because they always made me feel very special. If you are lucky enough to be a grandparent, you have a chance to make someone feel extraordinary. If you are the grandparent of a child with Tourette Syn-

drome, you have been given an unprecedented opportunity to help that child develop a sense of self and provide the tools needed to become successful adults. Being a grandparent is a gift and a responsibility.

In this issue of the TSA newsletter, we are featuring a story on the influence of grandparents on the lives of children with Tourette Syndrome. We think it's a tribute to the many people who provide support and love to children who often find the world to be a less than understanding place. We are grateful to all of our grandparents—past, present and future—who make the lives of our children special and filled with love.



Judit Ungar

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Tourette Syndrome Association, Inc.
Founded 1972

Letters

My son was diagnosed in October. He is nine years old. We held a tag sale and chose TSA as our charitable donation. Thank you for all you do to help people with Tourette! I guess this is just the beginning for us. — *M.M. of PA*

My son Eric was diagnosed with Tourette when he was seven years old. Your help got us through the tough times. When he was twelve the symptoms disappeared. We don't know why. He's sixteen and everything is great! — *T.C. of FL*

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Family PORTRAIT

Bruce Ochsman is a Senior Vice President at UBS-PaineWebber. He is forty-five and lives with his wife and two children in Bethesda, Maryland.

TSA: The impact of TS varies from person to person. What has been the biggest impact of TS on your life?

Bruce Ochsman: Honestly, as tough as having tics out in the open has been, I think some of the ancillary problems are much tougher to deal with—specifically OCD. For me OCD translates into anxiety, stress and obsessive thoughts. It makes it very hard for me to relax and let go. My mind is always working, always active, which, by the way, fuels me in business and makes me very goal oriented, but . . .

When I was younger the tics were a big problem. Everybody made fun of them in high school and early adulthood. Tics make you feel like the center of attention and OCD makes you feel like people are always looking at you, laughing at you. Now my tics don't really bother me.

TSA: What was it like when you were a child?

Ochsman: I wasn't diagnosed until I was nineteen. I went to doctors for years and kept being diagnosed with childhood tics that would go away or some kind of psychological problem. Since I'm the youngest of five, I was told my tics were a way of getting attention. Finally when I was nineteen a psychiatrist diagnosed me. It took him ten minutes of conversation!

TSA: How did your family cope?

Ochsman: My symptoms started when I was ten and got progressively worse. At first no one knew what it was, but there wasn't any hostility. They'd tell me to stop, but after a few years they realized that there was really something wrong. My mother always knew that, felt it. I think my father internalized some of the blame. The fact that it took so long to figure out. All those years of telling me to stop it, but now he's fine.

I grew up in a wonderful family. We're all very close. So when they told my parents I was trying to get attention it never really made sense. Back then you really listened to doctors. I guess my family tried to treat me nicer. They never teased me about my tics. Just normal family teasing. Being the youngest I was the most spoiled. I got to do everything, they

paved the way. So after ten minutes that psychiatrist said "you really don't hate your family."

I came from a family where you were supposed to be the best you could be. I knew there was something wrong. They knew it too, but I had to go out and live like everyone else. Even if I didn't want to go someplace or do something I had to. They didn't coddle me. Maybe I would have liked just a little more coddling. I had a wonderful, functional family.

TSA: Has TS had an impact on other important relationships, and on your education and work?

Ochsman: The fact is, TS impacts on everything I do. Relationships, school, everything. Every two or three seconds I get reminded that something is going on. I had to make allowances, explain it when I was dating, feel self-conscious during quiet time at school, worry about bothering other people during a test. For years I didn't sit in the middle of a restaurant and I'd sit in the back row of movie theaters. But now I don't care. It took me a long, long time to figure it out and stop caring so much.

TS is invasive. It's on my mind. It's part of me. I don't like it but it never stopped me from doing things. I adjusted. I've done nearly everything I wanted to do. The only thing I didn't do was learn to fly a plane. I went to college and law school. I'm married and I have kids. I just have to make allowances for the TS in everything I do.

My wife knew after our first date and she is cool with it. And it was much worse back then. Now I'm taking medication and it's been much better for the last three or four years.

TSA: What's been your experience with medication?

Ochsman: It took me twenty-one years to find the right medication, ten years to find the right combination. I tried 27 or 28 drugs and combinations to find the right one. I was looking for the least amount of side effects. Some of the medications stopped my tics, but the side effects were

horrendous. I couldn't take them. I had to find a balance between tics and side effects. Also, all of the medications seem to slow your metabolism and cause weight gain. I'm on Risperdal now, and take a very small amount, just enough to take the edge off.

TSA: Stress has a big impact on people with TS. Do you do anything to help alleviate your stress?

Ochsman: I work out. I'm not a fanatic, but I have a little gym in my house. I like to go on the treadmill—and just go mindless. I play sports too. I love golf but that's not athletic. Golf is about being calm and peaceful. My tics are worse when I'm stressed out, and I have a lot of stress at work. I also listen to music. Doing things with my kids also relieves stress, playing sports with them. Working out is also good for weight control.

TSA: TS is in the media a great deal lately. Some of the presentations are more realistic and more positive than others. What do you think of the role of the media in increasing awareness?

Ochsman: They call it artistic license. I see both sides of the equation. You need the media to educate, but the media needs to sell and the most outrageous is often the most interesting. They've done a phenomenal job in getting people to know there is something called TS, but it's up to TSA to go into schools and do proper presentations. Some media attention is better than others, PBS and the Discovery Channel have done a better job than some of the talk shows. I'd rather it be in the media so people learn about it. Most people understand that the media play up differences of all kinds, and creates caricatures. The first time I heard a mention of TS was in a comedy with Whoopie Goldberg and I thought—at least they

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If You Are Moving . . . or are receiving duplicate copies of this Newsletter—please let us know so that we can update our mailing list. To update, we need both your old and new addresses.



Ask The MEDICAL ADVISORY BOARD

Kate Kompoliti, M.D., Assistant Professor of Neurological Sciences, Rush-Presbyterian-St. Luke's Medical Center, Department of Neurological Sciences



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



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 than 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.



Ask The EXPERT

This issue's expert is Maura Kyne of the Information and Referral Services office at TSA national. Ms. Kyne and her colleagues field a variety of inquiries every day. Here are a few of the most frequently asked questions.

How did my child get Tourette Syndrome?

Genetic studies indicate that TS is inherited. With each pregnancy, there is about a fifty percent chance that the genetic vulnerability to having TS symptoms will be passed on from parent to child. Depending on how the genes are expressed, a person may be diagnosed with TS or may exhibit a different tic disorder or may have symptoms of obsessive compulsive disorder without any tics at all. The gender of the child also influences how the gene is expressed. Males are three to four times more likely to display TS symptoms than females.

What is the cause of Tourette Syndrome?

Although research has been conducted, no definite cause has been identified. Re-

search evidence does support the notion that TS is caused by the abnormal metabolism of several brain chemicals or neurotransmitters including dopamine and serotonin.

Is TS the reason my child experiences academic problems in school?

There are instances where symptoms of TS may affect classroom performance. Sometimes special educational assistance is needed because a child may have severe tics, ADHD, OCD, or other learning difficulties which contribute to possible poor performance. When this is the case, the school can make accommodations for these children in order to help improve their performance. For example, if children have poor handwriting, they may be

allowed to use a computer instead of writing. They may also be given untimed tests and permission to leave the classroom in order to express tic movements in private.

How is TS diagnosed and treated?

There are no specific medical tests that can identify this condition. Therefore, a diagnosis is made after taking a careful family history and by observing the symptoms. When needed, there are different medications used to help reduce TS symptoms. These medications include atypical neuroleptics, neuroleptics, anti-hypertensive drugs, anti-depressants, etc. Each person reacts differently to the medications so it may require periods of trial and error until the right prescription and dosage for that individual is found.

TSA 2003 National Golf Tour

An exciting year of golf is at hand as TSA rolls out its 2003 National Golf Tour. Beginning on Saturday April 26, join us at the magnificent Eagles Golf Club in Tampa Bay, Florida for an early morning shotgun tee off. On Monday, June 23, 2003, it's the wonderful Ravinia Green Country Club in Riverwoods, IL, north of Chicago. Monday, August 4, is the date for the first of two New York outings, this one is at the historic Wykagyl Country Club, in New Rochelle, just north of New York City, home of the LPGA Championship. Then it's on to the world renowned Westchester Country Club, (home of the Buick Open) in Rye, New York, on September 22. For more information about these events, and information about starting an outing in your area, please call the development office.

LD OnLine is the comprehensive online resource on learning disabilities for teachers, parents, and kids. If you would like to see more of LD OnLine, please visit them soon at <http://www.ldonline.org>.

Bruce Ochsman Family Portrait (continued from page 3)

think the public knows what it is. Maybe we're doing our job?

In the years I've been involved with TSA the time of diagnosis and increase in education of the public have been incredible. I remember when my friend took his medical boards to get his license. I was thrilled because there were more questions on TS than on the mumps—two on TS, one on the mumps.

TSA: Do you have any advice for the parents of kids with TS? And for the kids themselves?

Ochsman: The reason I was able to do so much is that that I was given the self confidence from my parents and family. I was included in everything, anywhere we went. Quite honestly, I was told to go, forced to go, and never allowed to use my tics as an excuse.

I would recommend open communications. That's the most important. Tell them that they are not alone, that nothing is wrong with their intelligence. Kids will have fears and uncertainties. They might need some more allowances made for TS. Talk to your kids. Get involved in their school, advocate for your kids. It may not be politically correct, but I believe in real

parenting. My kids know who is the boss, and parents need to stay in charge.

TSA: Tell us about your involvement with TSA.

Ochsman: I've been involved since 1983 or '84. I've been amazed at the quality of the volunteerism, the level of commitment and the quantity of time that people put in. People from all around the country and from the medical community as well, their involvement with TSA is wonderful.

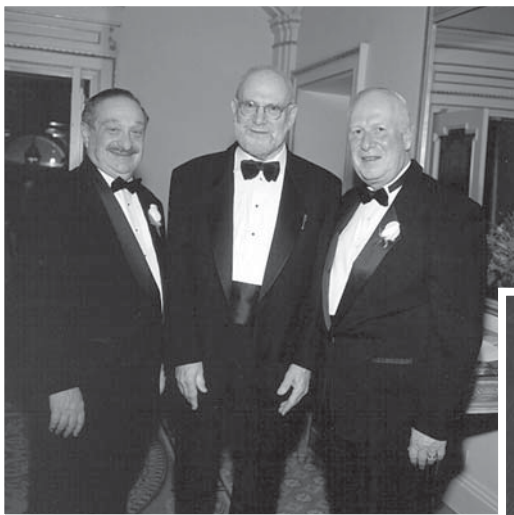
TSA is a real grass roots organization. It was started by parents who wanted to help their kids, and now—whatever the size—the organization still has the same basic concerns. There is nothing more powerful than parents concerned about their children. At some point we will succeed with the research because the passion is still there and it's never wavered. The people I met twenty years ago are still working and more and more are getting involved daily.

I was at the national conference and I looked around the dinner dance. Having tics was more common than not. It was normal to let them out. People with TS are life's dancers. ■



Dining + Dancing = Awareness and Support

TSA's Dinner Dance 2002 was held on November 20 at the Pierre Hotel in New York City. As in years past, the event was a tremendous success.



(l-r): Honorees Dr. Gerald Erenberg, past Chairman of TSA's Medical Advisory Board; Dr. Oliver Sacks, renowned physician and author; Robert W. Fiondella, Chairman and CEO of The Phoenix Companies



Dr. John Walkup, Chairman of TSA's Medical Advisory Board presenting award to Dr. Gerald Erenberg



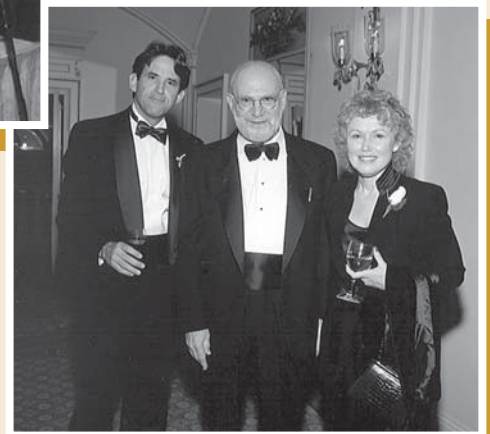
(l-r): Chairman of the Board Fred Cook; Michael Bamberger of Sonnenschein, Nath & Rosenthal; Sharon Cook



(l-r): Polly Draper with Nat *(left)* and Alex *(right)*; Judit Ungar; Michael Wolff



Dennis Squilla & Diane Mallah, Board Members & Chairs of TSA's Corporate & Professional Council



(l-r): Board Member Alex Greene; Dr. Oliver Sacks; Board Member Alice Kane



(l-r): Fred Cook with Luis Jorge and Lester Busby of Gate Pharmaceuticals



(l-r): Judit Ungar; Dr. John Walkup and Event Manager, Susan Cimini



(l-r): Youth Ambassadors Joriel Sharp and Kristen Nazzaro with TSA President Judit Ungar



Grandparents of Children with TS (continued from page 1)

to talk to people. I needed to learn. It makes you feel better.”

Barbara is also committed to working with TSA to help find new medications and a cure. “I also try to raise money for TSA so I have to be public. A lot of my friends send a donation when there’s a birthday. If I’m not active in some ways, I’m always vocal about it.”

“Baby-sitting is more than baby-sitting, it’s a way to form a strong bond.”

She feels protective of her grandsons and hopes that people who don’t understand TS won’t hurt them. The gap between the image of TS in the general media and the reality leaves many people with harmful impressions. People have told her that her grandchildren don’t have TS, because, “they don’t curse.”

“I think that as far as cases of TS go, we’ve been very fortunate. We caught it early and received care early, so they didn’t experience a lot of the personal infringements. I would say on a scale of 1 to 10, they have cases that are 3 or 4.”

Winslow and Alex

Winslow Remley has nine grandchildren. He and his wife move back and forth between their two homes, one in Virginia, the other in Florida. He spends a great deal of time with all his grandchildren, especially twelve-year-old Alex, his grandson with TS. Last November they attended the TSA National Conference together. Winslow thought it was a great opportunity to learn about TS and for Alex to meet other children with TS. Alex, a sports fan, is not a natural athlete so Winslow encourages his interest in sports photography as a way of becoming an integral part of the team.

“We have nine grandchildren. Alex is the third oldest. My wife and I adore children and we are very close with all of our grandchildren. Now that we’re both retired we spend a great deal of time with them (Alex and his two siblings). Baby-sitting is more than baby-sitting, it’s a way to form a strong bond. The kids are just as com-

fortable in our home as they are in theirs. We’re very close to them, maybe more close than usual because of their parents’ divorce. Alex and his younger sister and brother were crushed by the divorce. We’ve been married forty-seven years and I think that adds an element of stability to their lives. We can show them that people can get married and stay together long term.”

Alex’s TS symptoms developed when he was nine. The following three years have been a challenge. He’s very bright and attends a school for gifted children, where the teasing that many children with TS endure has been minimized. And yet he still dwells on, “Why me?” and has had difficulty making new friends.

“We’re very close, but every time I’ve tried to talk to him about TS he clams up or changes the subject. I know he trusts me, but it’s obviously a painful subject for him. I think he discusses it more openly with his mother. Puberty also affects his symptoms and I’ve sensed that he’s almost angry to have been singled out to have TS.”

Attending the TSA National conference together gave Winslow the opportunity he needed to discuss TS with Alex, at least in general. It was important to see that other people have TS and that Alex’s symptoms were not extraordinary.

“It was interesting to see how different family members address it—some talk openly about it, but others don’t. The conference was great—everybody was talking about TS. It wasn’t unusual. It was the most open he’s ever been about his condition. He saw some of the people with outbursts of profanity. He doesn’t do that and I think it helped him see that the glass is half full for him—not half empty. I’m not saying that he should take comfort in other people’s misery, but God just gives out different doses of the same problem. He was somewhat shocked at the severity of some of the tics.”

Winslow didn’t meet other grandparents at the conference, but he did connect

with many of the Virginia area families. It was important for him to meet parent members of the local chapter. The conference also gave Alex an opportunity to meet other children with TS, and Alex made a new friend among the participants in the children’s program. A believer in the power of peer group discussions, Winslow hopes that the next conference will feature guided discussion groups for Alex and the other kids his age.

“The two little guys hit it off really nice and had a good time. We intend to go back.”

Richard and Eric

Richard Sussman’s grandson Eric is now twenty-two and graduating from college. He’s bright, creative and well on his way to a successful career. But Eric had a tough time with a sudden onset of TS symptoms not long after he celebrated his Bar Mitzvah. Richard is very proud of Eric and has always been impressed by his grandson’s ability to communicate.

Even as a teenager, Eric articulated his feelings about TS with ease. “He writes beautifully and expressed his feelings very, very well.” Richard describes his grandson’s public speaking on TS as “at an almost professional level.”

When asked what he would most like to share with grandparents of younger children with TS, Richard reminded them to “stay tuned in.”

“Grandparents are very special people. It’s important to understand that you’ll be a sounding board for a child who is facing a very difficult time. The child will be looking for someone who will be supportive and grandparents are those people. Sometimes making or keeping friends is difficult for children with TS, so the importance of grandparents doubles. You have to be open to it. You’re going to be there for him when others turn away.”

The role that grandparents play in the lives of children with TS cannot be overestimated. They can be role models, resources, baby-sitters and most of all—special buddies. Anyone who’s lucky enough to be a grandparent—or to have one—knows unconditional love. ■



Chapter Update

The Winter of 2002 was a busy time for TSA chapters across the country. In addition to a wide variety of fun events—including a family fishing trip on Long Island and a Rocky Mountain Region Casino Night—chapters hosted conferences that offered members both information and support. TSA Illinois focused on Stress Control and TSA New York Hudson Valley, concentrated on teaching parents to cope with ADHD and OCD in their children.

Jeff Swift, TSA Massachusetts Chair, spoke at the Human Genetic Disorder Research Project, a semester-long investigation by Harvard students into a variety of disorders. This unique program seeks to bridge the gap between conceptual discussions of and the dramatic, real life consequences of genetic disorders.

Media Success in Westchester is Blueprint for Other Chapters

The New York Golf Outing is an annual fundraising success for TSA. The September 23rd outing was also a media triumph, and other chapters are following the golf outing's lead. Whether a chapter is staging a bake sale, bowling tournament, casino night, bike-a-thon, wine tasting or educational conference, promotion is the key to a successful event. Forming alliances with local business organizations can also pull in large numbers of participants. Westchester worked with the local construction industry, drawing on a network of business connections and friendships.

Planners should take notes:

- send announcements/press releases to the local media well in advance of the event date and then follow up the announcement with a phone call

- include photos of some of the organizers and/or featured guests whenever possible
- add local radio and television outlets to your media list, try to target the information to the right person at each TV and radio station
- send a second press release right after the event, include photos when available
- cooperate or cosponsor the event with a local business organization (manufacturers, retailers, banks, etc.), these business organizations have trade publications which are often eager to support their industry's charitable efforts
- work your phone books, the personal networks of chapter members are a great resource for all sorts of help and support in the planning, promotion and execution of an event

Three TSA Scientific & Medical Meetings in Atlanta

In early February, TSA's Medical & Scientific Advisory Boards and International Consortium for TS Genetics, met in Atlanta, GA. Volunteer members representing the fields of neurology, psychiatry, pediatrics, and genetics met to discuss issues of TS treatment and to review TSA's 2003-04 research grant requests.



Medical Advisory Board

Seated (l-r): J. Ungar (TSA President), S. Levi-Pearl (TSA VP Scientific & Medical Programs), L. Scahill, T. Lang, T. Murphy

Standing (l-r): J. Juncos, S. Zinner, K. Kompolti, C. Budman, J. Walkup (Chair), P. Sandor, J. Mink, C. Berlin, R. Kurlan, J. March, M. Redman (TSA Board of Directors)



International Consortium for TS Genetics

Seated (l-r): M. Grados, C. Barr, F. McMahon, S. Levi-Pearl (TSA), A. Verkerk, P. Michael Conneally, N. Swerdlow

Standing (l-r): G. Rouleau, J. Rice, C. Ilmann, L. Campbell, H. Coon, Y. Dion, N. Freimer, L. Hendrickson, J. Leckman, P. Heutink, B. Oostra, C. Hurst, P. Sandor, D. Pauls



Scientific Advisory Board

Seated (l-r): S. Levi-Pearl (TSA), M. DiFiglia, P. Michael Conneally, N. Swerdlow (Chair), G. Erenberg

Standing (l-r): J. Walters, J. Ungar (TSA), F. Xavier Castellanos, J. Paulsen

Back row (l-r): S. Paydar (NIH Observer), J. Walkup, L. Brady (NIH Observer), F. McMahon, A. Levey, J. Csernansky, K. Frey, M. Denkla, P. Hollenbeck, M. Redman (TSA), S.B. Caine, J. Rice, J.P. Vonsattel



Summer Camp for Kids with TS

Finding the right camp for a child with TS can be a challenge, but good communication and solid planning can lead to a great summer experience. Starting your research early can increase your chances of finding the camp that best meets your child's needs. In some localities the TS community operates facilities particularly attuned to managing children with TS symptoms. There are other camps that direct their services to children with ADHD, ADD and OCD. Some of these camps have experience with campers affected by TS.

A good place to start is with a clear understanding of your child's individual interests and needs, level of independence and medical condition. Some camps emphasize athletics, others focus on computer skills, nature studies or the arts. Some camps require children to be comfortable "on their own" while others provide more supervision. It's important to figure out what your child needs before you start looking at brochures and web sites.

A good match between camper and camp is key to a happy summer. Talk to your child about his or her expectations, and make a realistic assessment of your child's level of maturity. With or without TS, not every child is ready for a whole summer away from home. A trip of shorter duration, or a camp with more supervision, might be the right choice for a great summer.

Parents should also research the camps and feel free to ask questions.

- Find out the camp's "philosophy." Does the camp stress participation by all campers in every activity or does the camp encourage individual children to follow their own moods?
- Is the atmosphere competitive or laid back?
- Do the camp activities appeal to your child?
- What is the staff to camper ratio?
- How does the camp handle emergencies?
- What kind of medical staff is on hand?
- If possible, go in person and check out how the camp is run.
- Plan to visit the camp during the actual session.
- Ask about the type of sessions are offered: two, four, six weeks.

- And, just in case, find out what the refund policy is before there is a problem.

For information about specific camps, ask your local TSA chapter and other parents. They may be the best source of first hand knowledge about camps in your area. The following list of camps and websites will aid you in your search for a suitable camp for your child. TSA maintains a growing list of facilities. Often TSA listings reflect suggestions offered by member families. Feel free to contact TSA's Information and Referral at 718-224-2999 Ext. 245 or 226 with any additional questions. Good luck and best wishes for an enjoyable summer.

The postings below are included in the TSA lists for Summer Camp Resources. These facilities have represented a familiarity with Tourette Syndrome and an ability to provide appropriate supportive services. TSA does not have the capacity to independently visit facilities or verify claims. The listings are provided for informational purposes only. As with many other services, families are advised to thoroughly interview and visit with summer camp providers before making their selection.

Camp Winston
110 Eglinton Ave. W.,
Suite 302
Toronto, Ontario M4R 1A3
416-482-4489

Camp Courage of Iowa
RR 2 PO Box 557
Monticello, Iowa 52310
319-465-5916

Ramapo Anchorage Camp
PO Box 266
Rhinebeck, NY 12572
845-876-8403
fax: 845-876-8414

Tourette Syndrome
Camp Organization
6933 N. Kedzie #816
Chicago, Illinois 60645
773-465-7536
Email: Scott63@prodigy.net
www.tourettecamp.com

Online Resources:
www.aca-camps.org
www.kidscamps.com
www.camping.org
www.parentsoup.com/
summercamp
www.summercamp.org

Victories



Laura Rasmussen is already a star. When she was diagnosed at five, her doctor encouraged her parents to help build her self esteem. It worked. At nine, Laura is bubbly and outgoing. She loves performing and doesn't get nervous. She was recently recruited by a talent agency. Her family is not sure where Laura's talent will lead her, but they are certain that the journey is more important to their little star than the destination.



Ten-year-old D'arcy Finnegan is a winner! His soccer team has won every tournament they entered including the prestigious Atlanta Cup, and is ranked number one in Florida. D'arcy's mother showed him the recent TSA newsletter interview with New Jersey Metrostar Tim Howard. It inspired D'arcy to even greater athletic achievement and the family hopes that D'arcy's success will inspire other kids with TS.



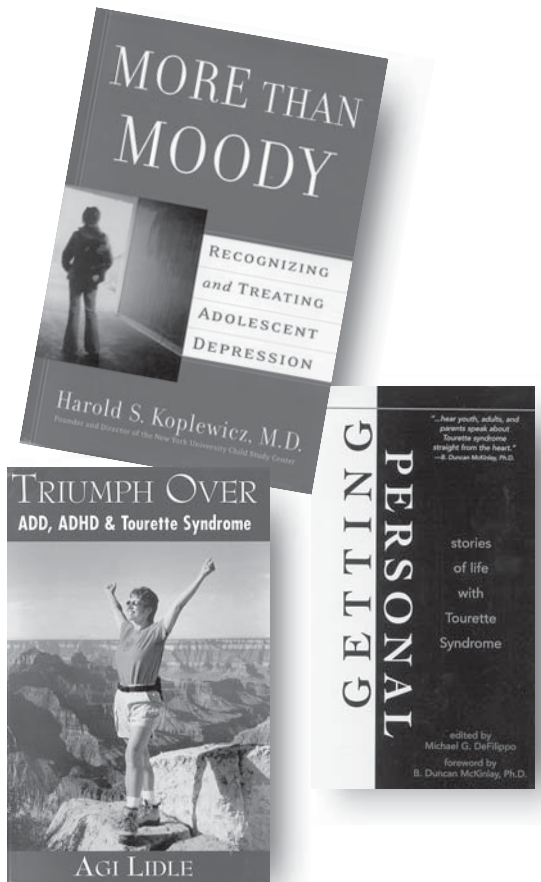
Off The BOOKSHELF

More Than Moody, Recognizing and Treating Adolescent Depression by Harold S. Koplewicz, M.D. As the founder and director of the New York University Child Study Center, Koplewicz tackles adolescent depression—its causes and its treatments. The book is a guide for parents, healthcare professionals and young adults, helping to distinguish between the angst of normal adolescence and actual depression. This book is recommended by James T. McCracken, M.D. and James Leckman, M.D. Publisher: Putnam books, www.penguinputnam.com, \$25.95.

Getting Personal, Stories of Life with Tourette Syndrome edited by Michael G. DeFilippo. A technical writer and first-time author, Michael DeFilippo was diagnosed with TS in 1998. *Getting Personal* is a compilation of more than 20 stories of real people with Tourette Syndrome. The fore-

word is by B. Duncan McKinlay, Ph.D. Publisher: Second Chance Publishing, www.secondchancepublishing.com, \$16.95.

Triumph Over: ADD, ADHD & Tourette Syndrome by Agi Lidle. Herbalist and inspirational speaker Agi Lidle was diagnosed with TS and ADD in early childhood. Her book details her own personal triumphs and tribulations and how she's managed to deal with the symptoms of her disorders, using a combination of positive thinking, alternative therapies and a natural diet. The book also includes an extensive natural recipe cookbook and guide to healthy eating. Publisher: A Better Life Publications, 1-866-990-5433, www.abetterlife.info, \$19.95 plus S & H.



Calling All Runners

TSA is happy to announce that it has secured a limited number of spots in one of the world's leading and most prestigious Marathon events, the Marine Corps Marathon in and around Washington, D.C. These will be made available to TSA members and friends on a first-come-first-served basis with a commitment to raise a minimum of \$1,000. This is the first event of what we hope will become a nationwide running program for TSA. If you are a runner who regularly runs in Marathons, or wish to, we would like to hear from you as we build this new program. Please contact the TSA Development Office at 718-224-2999, ext. 230 or e-mail us at: mark.levine@tsa-usa.org for further Marine Corps Marathon information or to discuss other running program ideas.

Leave A Legacy: Protect Your Estate

The TSA Legacy Society provides financial security for your heirs, while supporting the TSA mission. Through planning for your financial future, both when working and after retirement, The Legacy Society can play an important role in protecting your assets while reducing your income tax burden. From wills and bequests, to gifts of insurance, to charitable annuities that keep your tax reduced income flowing, there is a plan for you. Contact Mark Levine in the Development Office at 718-224-2999, ext. 230 for further information about how you can put your estate to work for both you and TSA. All contacts and discussions maintain the highest level of confidentiality.

victory

Not everyone's Bar Mitzvah makes the news, but the story of Brandon Sherman's traditional passage into manhood was covered by the *San Diego Union-Tribune*. Brandon has been coping with TS tics and OCD for as long as he can remember, but this student at the San Diego Jewish Academy read his selection from the Torah with style. Brandon has also built a solar car, speed reads and writes poetry.

JOIN THE GRANDPARENTS CLUB

Show your support for your grandchildren and become a part of TSA.

For more information call:
718-224-2999

If you would like to access our newsletter online, please give us your e-mail address. If you are a member, we will give you a password . . . e-mail to ts@tsa-usa.org.



TSA: JOIN OR RENEW NOW

Start/Renew my Membership in TSA, Inc.
at the following level:

- \$5,000 Lifetime Membership
- 1,000 Benefactor
- 500 Patron Member
- 250 Sustaining / Corporate Membership
- 125 Contributing Member
- 100 Physician Membership
- 90 Individual Membership plus support
for a Scholarship Member
- 60 Family Membership (2 votes)
- 60 Allied Professional (Ph.D., CSW, etc.)
- 45 Individual TSA, Inc. Member

Additional Contributions

- \$ _____ Research Fund
 - \$ _____ My local TSA chapter
 - \$ 45. Support for Scholarship
 - \$ _____ I cannot afford \$45 dues. However,
enclosed is a donation to support
the work of the Association.
 - I cannot afford membership. Please
enroll me as a TSA Scholarship
Member for the next year.
- \$ _____ Total Enclosed

Check/M.O. enclosed (payable to TSA, Inc. – U.S. funds only please)

MasterCard Visa American Express Expiration date _____

Card number:

Signature _____

Family membership (same household), please include two (2) names for two (2) votes:

Name 1 _____

Name 2 _____

Street _____

City _____

State _____

Zip _____

Daytime phone number _____

e-mail address _____

Thank you for your membership contribution.



42-40 Bell Boulevard ■ Bayside, NY 11361-2820

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Organization
U.S. POSTAGE PAID
Tourette Syndrome
Association, Inc.

SAVE THE DATE

The TSA National Conference is
moving from the Fall to the Spring

We will meet again in Alexandria, Virginia
April 23-25, 2004. That is only a year from
now, so be sure you mark your calendar.

A great program is being planned.

Check the summer issue for details.