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What special role can grandparents play in the lives of children with Tourette Syndrome?

Children with TS often face numerous challenges as they develop and grow toward maturity. Building the self-confidence to sustain them through potential teasing and discrimination can at times be a difficult task. Loving grandparents are an important resource to help children with TS feel good about themselves. The unconditional love, support, and encouragement that involved grandparents can provide is a powerful tonic for building self-esteem. Research has borne this fact out. (Kendall, Scherman et al.,)*

Ideally, grandparents are strong cheerleaders who positively influence their grandchildren toward success in school, extracurricular activities, and relationships. In this scenario the parents provide the necessary advocacy to smooth out bumps within the child's environment as well as discipline to mold controllable, non-tic behaviors while Grandparents empathize with the child, identifying how he or she feels, providing sympathy and support and becoming a trustworthy confidant.

The unconditional acceptance of their grandchild's inherent value will engender a reciprocal love in the child, not unlike the relationship that develops between two best friends. Parents can aspire to this role as well, although it becomes harder due to the intrinsically greater (though necessary) disciplinary aspect of the parental relationship. Strong positive bonds that begin in early childhood are thought to fortify and enhance one's adjustment to the demands of the outside world.

What about some of the old-fashioned parenting suggestions that grandparents remember from raising their own children—children with TS at a time when there was less known about the disorder?

Of course, the level of knowledge and acceptance that a grandparent brings to the relationship is critically important. Parents who raised children with TS in the 1960s and 70s faced more limited information and support than is accessible today.

No doubt, in the absence of knowledge, many well-intentioned parents may have resorted to counterproductive, harmful techniques such as shaming, cajoling or bargaining in an effort to eliminate their

children's tics and/or compulsions. These unhelpful methods have never been successful in permanently reducing tics and can actually exacerbate them and cause serious damage to a child's self-esteem.

Thankfully, national TSA, local chapters, support groups, this newsletter, the popular media, and other resources have helped to reduce ignorance and the collateral damage it causes. Knowledge is empowering. Grandparents who regret having made previous mistakes as parents of a child with TS, could benefit from the opportunity to get it right the second time around. Also, grandparents with or without TS themselves, may provide useful objective advice when parents become wary. The great Roman author, Marcus Cicero said "Of all nature's gifts to the human race, what is sweeter to a man than his children?" The intensity of that pleasure for grandparents is almost always as great if not more so. Harnessed properly, grandparents' support and love can be wonderful medicine for helping children with TS to grow up into productive, well adjusted people.

* Kendall, SL. (1999). *Grandparents Tales: Stories Our Children Need to Hear. Dissertation Abstracts International Section A: Humanities and Social Sciences*. July. 57(1-A): 0028. Scherman, A, Eftimiadis, MS, Gardner, JE, McLean, HM. (1998). *The Role of Panamanian Grandmothers in Family Systems that Include Grandchildren with Disabilities. Educational Gerontology*. April-May. 24(3): 233-246.

Leave a Legacy to TSA

The Legacy Society is the estate planning program of the Tourette Syndrome Association. It is designed to protect your heirs while assuring your continued support of TSA. Through bequests, trusts, annuities and similar financial vehicles, you may be able to lessen or eliminate the tax burden while assuring that assets are distributed as you wish. Everyone is welcome to become a part of the Legacy Society. Call the national Development Office at extension 230 for more information or to request our Planned Giving publication.

Chapter News

Training the Trainers

National TSA and local TSA Chapters have formed an Educational Partnership to Train the Trainers. The Development Department of national TSA works with local chapter leaders to write grants to cover the expenses of special meetings where, TSA board member, Chapter President and educator, Sue Conners, visits local chapters and presents the TSA Educator Curriculum Program to entire school districts by training the district trainers. These trainers are armed with the information they need to "educate" the educators, school nurses and administrators. At the TSA Florida training, 45 people attended this intensive all-day presentation and were joined by parents for the afternoon session.

New Jersey Educators

Rutgers University and TSANJ developed accredited workshops for teachers, social workers, psychologists and medical doctors. Two were held during the last school year and three or four are planned for this year. One to two hundred professionals attend each of these enlightening sessions. TSANJ also initiated a program which reaches out to educators who attend its accredited Inservice at local community colleges. During the 2001/2002 school year this program will expand to reach all 19 community colleges.

TSA Annual Membership Business Meeting

Saturday, October 27, 2001
2 pm - 4 pm
North Shore University Hospital
Community Drive
Manhasset, New York

