

Information about:

Tourette's Syndrome

Revised September 2009



Vermont
Family
Network

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Introduction

Information About Tourette's Syndrome is part of a series of information packets developed by the Vermont Family Network (VFN). Designed to provide basic information, the packet includes fact sheets, articles, advocacy tips, and resources for families of children with special needs and for the professionals working with them.

After reading the packet, we hope that you'll have a greater understanding of Tourette's syndrome and the ways in which parents and professionals can support children at home, in school, and in the community. We've selected information from a variety of sources, and many articles are on the Internet.

Thank you to BEST (Building Effective Strategies for Teaching), Vermont Department of Education, for making this publication possible. Thanks also go to the organizations and authors who gave us permission to use their articles and fact sheets. Use of any specific articles in this packet is meant for information purposes only and doesn't indicate any endorsement on the part of VFN of the views and opinions of the authors.

Because your comments are important to us, we've included a reader's response form at the end of the packet. Please take a few minutes to fill it out and return it to our office. Thank you.

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Tic Disorders

Publication Number 35

A tic is a problem in which a part of the body moves repeatedly, quickly, suddenly and uncontrollably. Tics can occur in any body part, such as the face, shoulders, hands or legs. They can be stopped voluntarily for brief periods. Sounds that are made involuntarily (such as throat clearing) are called vocal tics. Most tics are mild and hardly noticeable. However, in some cases they are frequent and severe, and can affect many areas of a child's life.

The most common tic disorder is called "transient tic disorder," which may affect up to 10 percent of children during the early school years. Teachers or others may notice the tics and wonder if the child is under stress or "nervous." Transient tics go away by themselves. Some may get worse with anxiety, tiredness, and some medications.

Some tics do not go away. Tics which last one year or more are called "chronic tics." Chronic tics affect less than one percent of children and may be related to a special, more unusual tic disorder called Tourette's Disorder.

Children with Tourette's Disorder have both body and vocal tics (throat clearing). Some tics disappear by early adulthood, and some continue. Children with Tourette's Disorder may have problems with attention, concentration, and may have learning disabilities as well. They may act impulsively, or develop obsessions and compulsions.

Sometimes people with Tourette's Disorder may blurt out obscene words, insult others, or make obscene gestures or movements. They cannot control these sounds and movements and should not be blamed for them. Punishment by parents, teasing by classmates, and scolding by teachers will not help the child to control the tics but will hurt the child's self-esteem.

Through a comprehensive medical evaluation, often involving pediatric and/or neurologic consultation, a child and adolescent psychiatrist can determine whether a youngster has Tourette's Disorder or another tic disorder. Treatment for the child with a tic disorder may include medication to help control the symptoms. The child and adolescent psychiatrist can also advise the family about how to provide emotional support and the appropriate educational environment for the youngster.

Further information about Tourette's Disorder is available from
The Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, NY 11361-2861
<http://tsa.mgh.harvard.edu/>
718.224.2999.

For additional information see Facts for Families:

#6 Children Who Can't Pay Attention
#21 Psychiatric Medication for Children
#52 Comprehensive Psychiatric Evaluation, and
#47 The Anxious Child.

See also: *Your Child* (1998 Harper Collins)/*Your Adolescent* (1999 Harper Collins).

The American Academy of Child and Adolescent Psychiatry (AACAP) represents over 6900 child and adolescent psychiatrists who are physicians with at least five years of additional training beyond medical school in general (adult) and child and adolescent psychiatry.

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To order a complete set of loose-leaf black and white Facts for Families, for \$25.00 or to order a spiral bound edition of the series for \$35.00, contact AACAP's Nelson Tejada: 202/966-7300 ext. 131, or 1.800.333.7636 ext. 131.

Free distribution of individual Facts for Families sheets is a public service of the AACAP Special Friends of Children Fund. Please make a tax-deductible contribution to the AACAP Special Friends of Children Fund and support this important public outreach. (AACAP, Special Friends of Children Fund, P.O. Box 96106, Washington, D.C. 20090).

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Tourette's Syndrome

Tourette's disorder, or Tourette's syndrome (TS) as it is frequently called, is a neurologic syndrome. The essential feature of Tourette's are multiple tics that are sudden, rapid, recurrent, non-rhythmic, stereotypical, purposeless movements or vocalizations.

*What are the symptoms of Tourette's syndrome?*¹

- Both multiple motor and one or more vocal tics are present at some time during the illness, although not necessarily simultaneously
- Occurrence many times a day nearly every day or intermittently throughout a span of more than one year
- Significant impairment or marked distress in social, occupational, or other important areas of functioning.
- Onset before the age of 18²

Symptoms can disappear for weeks or months at a time and severity waxes and wanes.

What are the first tics that may be characteristic of TS?

Usually, the facial tic, such as rapid blinking of the eyes or twitches of the mouth, may be the first indication a parent has that their child may have TS. Involuntary sounds, such as throat clearing and sniffing, or tics of the limbs may be an initial sign in other children.

Are any other symptoms associated with Tourette's?

Approximately 50 percent of patients meet criteria for attention deficit hyperactivity disorder (ADHD) and this may be the more impairing problem. Approximately one-third of patients meet criteria for obsessive-compulsive disorder (OCD) or have other forms of anxiety. Learning disabilities are common as well as developmental stuttering. Social discomfort, self-consciousness and depressed mood frequently occur, especially as children reach adolescence.

What causes these symptoms?

Although the cause has not been definitely established, there is considerable evidence that TS arises from abnormal metabolism of dopamine, a neurotransmitter.³ Other neurotransmitters may be involved.

Can TS be inherited?

Genetic studies indicate that TS is inherited as an autosomal dominant gene but different family members may have dissimilar symptoms. A parent has a 50 percent chance of passing the gene to one of his or her children. The range of symptomatology varies from multiple severe tics to very minor tics with varying degrees of attention deficit-disorder and OCD.

Are boys or girls more likely to have TS?

The sex of the child can influence the expression of the TS gene. Girls with the gene have a 70 percent chance of displaying symptoms, boys with the gene have a 99 percent chance of displaying symptoms. Ratios of boys with TS to girls with TS are 3:1.

How is Tourette's syndrome diagnosed?

No blood analysis, x-ray or other medical test exists to identify TS. Diagnosis is made by observing the signs or symptoms as described above. A doctor may wish to use a CAT scan, EEG, or other tests to rule out other ailments that could be confused with TS. Some medications cause tics, so it is important to inform the professional doing the assessment of any prescribed, over-the-counter, or street drugs to which the patient may have been exposed.

What are the benefits of seeking early treatment of TS symptoms?

When a child's behavior is viewed as disruptive, frightening, or bizarre by peers, family, teachers, or friends, it provokes ridicule and rejection. Teachers and other children can feel threatened and exclude the child from activities or interpersonal relationships. A child's socialization difficulties will increase as he reaches adolescence. Therefore, it is very important for the child's self-esteem and emotional well-being that treatment be sought as early as possible.

What treatments are available for TS?

Not everyone is disabled by his or her symptoms, so medication may not be necessary. When symptoms interfere with functioning, medication can effectively improve attention span, decrease impulsivity, hyperactivity, tics, and obsessive-compulsive symptomatology. Relaxation techniques and behavior therapy may also be useful for tics, ADD symptoms, and OCD symptoms.

How does TS affect the education of a child or adolescent with TS?

TS alone does not affect the IQ of a child. Many children who have TS, however, also have learning disabilities or attention deficits. Frequently, therefore, special education may be needed for a child with TS. Teachers should be given factual information about the disorder and, if learning difficulties appear, the child should be referred to the school system for assessment of other learning problems.

What is the course of TS?

Some people with TS show a marked improvement in their late teens or early twenties. However, tics as well as ADD and OCD behavior, may wax and wane over the course of the life span.

¹ According to the *Diagnostic and Statistical Manual of Mental Disorders* (4th Edition), or DSM-IV

² This is a change from the former edition, DSM-III-R, that set maximum age of onset at 21 years of age.

³ A biochemical substance that transmits nerve impulses from one nerve cell to another at a synapse.

Reviewed by Charles T. Gordon, III, M.D., Assistant Professor of Psychiatry
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Helpline Fact Sheet, National Alliance for the Mentally Ill, Colonial Place Three, 2107 Wilson
Blvd., Suite 300, Arlington, VA 22201-3042. 705-524-7600
Helpline: 1-800-950-NAMI, www.nami.org

For Parents of Children Newly Diagnosed with Tourette's Syndrome

Preface

In 1989, my son was officially diagnosed with Tourette's and ADHD. Eventually he would also be diagnosed with OCD. A few years later, when I realized my daughter also had Tourette's, I felt overwhelmed. How could both my children be "struck down" this way? Remembering the confusion and fear I felt back then, and having spent over 13 years on our journey now, I wish I'd known then what I know now. If you are a parent of a newly diagnosed child, you may also be experiencing a lot of intense emotions. This is my message to you.....

Dear Parent,

If you've only recently learned that your child has Tourette Syndrome, this can be a confusing and stressful time for you. If you have been running from doctor to doctor for a while, you may feel relieved to finally have someone confirm that yes, there is something "wrong" and you weren't crazy to be so concerned. But at the same time that you might be feeling a bit of relief, you may be feeling a lot of other emotions as well -- grief, fear, and guilt are all reactions that parents may experience in the process of coming to accept their child's diagnosis. Educating yourself and coming to accept the diagnosis and situation takes time for most people. Give yourself a chance to get used to things.

If you're anything like I was/am, you will want to find and read everything you can. It can be overwhelming at the beginning, though, and you may want to read a bit and then give yourself time to absorb before going on to another section on this site. Similarly, as you read or visit online support groups or bulletin boards, remember that you are more likely to encounter parents or adults who have had the more severe cases. The folks who are doing just fine often don't feel a need to participate and are too busy just living their lives.

Many parents who hear the words "Tourette Syndrome" have an immediate dread that their child will land up with "coprolalia" (the uncontrolled swearing or socially unacceptable utterances). This image of Tourette Syndrome as the "cursing disease" is misleading as only a minority of patients with TS actually develop coprolalia. In this case, the public's image is largely due to media fascination with the more extreme or unusual cases. As you will discover on my web pages, there are many cases of very mild symptoms.

As a parent of a newly diagnosed child, one of your other immediate questions is likely to be, "Is there any way to tell if my child will have a severe case or a mild case?" The answer to that is "no." Just as there is no way you can know whether your child will be in the majority who will have a complete or significant remission. And no amount of worrying about it will prevent your child from going through the ups and down of tic symptoms, because that kind of "roller coaster" variability is the hallmark of Tourette Syndrome.

Worrying can increase your child's stress and make their symptoms worse, though. So let's think about how to support you so that you can support your child by helping your child accept that there will be times when they may experience some discomfort or difficulty from the tics and symptoms of their disorder. If you go "up and down" on an emotional roller coaster every time your child goes through a to-be-expected period of symptom worsening, you will land up exhausting yourself and not providing your child with the kind of support and parenting that s/he may need.

Unfortunately, there are no hard and firm answers out there for many of the most important questions parents have. Research on TS has tended to focus on the scientific or medication aspects, and very little attention has been paid to the kinds of issues parents often raise -- issues of how to respond to a child's symptoms or how to help the child in school if they're struggling. Expect to encounter controversy as you read on these topics. And recognize that there are many well-meaning people out there who will give you firm advice based on their own personal experience. Their experience may not be yours, however.

In the long run, much of what you learn about how to help your child will be trial and error -- informed by the experiences of those who have gone before you, but ultimately your trial and error. And isn't that true of all parenting?

If there are four thoughts I could impart to you as you begin your journey in understanding your child, it would be these:

Remember that your child is not a disorder, but just a child. Never lose sight of your child in the symptoms or any rough periods.

Not everything wrong or bad will be from "TS." Sometimes bad behavior is just plain old bad behavior. Learn what age-appropriate behavior is so that you don't fall into the trap of pathologizing everything or attributing it to a "disorder" when it is really the kind of behavior we expect from kids at that age.

Catch your child doing something good, and smile and share a hug. There are always difficult patches in childhood. Children who have TS will experience ups and downs just like any other child. If you place your child under a microscope watching anxiously for signs of TS, you will miss out on many opportunities to just enjoy your child. If you teach your child that everything they do that is unacceptable is from "their TS," you do them a disservice. Children need firm consistent loving structure and discipline to help them learn the boundaries and expectations. "Discipline" doesn't mean punitive consequences: it means "teaching." You are their most important role model.

Take care of yourself. Don't burn yourself out. Read in small doses if you start to feel anxious or overwhelmed. Make it a point to get away or out for some socialization and relaxation with friends.

You're Not Alone

Remember that you are not alone. Support is out there -- lots of it. Contact your local TS organization or chapter of TSA. Join the organization and attend parent support groups if you feel that you need an understanding ear or shoulder. If you're struggling

with your child's school, ask your local TS chapter about advocacy assistance. Some areas have a lot of resources, other areas don't. Find out what's available in your area so that you don't burn yourself out rediscovering the wheel.

TS is a syndrome. It is not a fatal disease. Your child sees him/herself through your eyes. If s/he sees you looking with fear or anxiety, that will affect her/him. If you get depressed, they will feel anxious and depressed. If they see you smiling and coping and finding humor and enjoyment in life, they will be more likely to find it, too. If you expect their childhood to be miserable, it probably will be. If you model and teach them realistic coping strategies and help them discover a sense of humor, they will thank you later on.

I wish you well as you begin your journey. My journey began over 10 years ago, and I still learn every day. My children have been my best teachers, as between them, they have probably managed to have almost every symptom imaginable. As you read my web pages, you will find materials that are based on my experiences as a mother, as a psychologist, and as an advocate for people with TS. I have been wearing all those hats for a while now. And with all of my hats on, I say to you:

Your child needs your understanding, acceptance, and support. You have the opportunity to make a world of difference in your child's life. Take that opportunity and make the most of it.

Leslie

Leslie E. Packer, PhD 1998

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From web site Tourette Syndrome 'Plus', www.tourettesyndrome.net

Specific Classroom Strategies and Techniques for Students with Tourette Syndrome

For Tic Symptoms

- Tests taken in a separate location with time limits waived or extended.
- Educate the other students who come into contact with the child with TS. TSA has a peer inservice entitled "Educating classmates about TS." An advocate from the local TSA chapter may also be helpful.
- Provide a refuge where the student may go to calm down, release tics or obsessions, e.g. the Nurse's Office, the School Psychologist's Office.
- Give the child frequent breaks out of the classroom to release tics in a less embarrassing environment, e.g. the bathroom, the drinking fountain, a real or made up errand to run.
- If tics are socially inappropriate (spitting, swearing, touching people inappropriately), it may be necessary to brainstorm possible solutions (e.g., a spitting tic could be resolved by giving the child a tissue to spit into).

For Fine Motor/Visual Motor Impairment

- The use of a word processor is a reasonable and necessary accommodation.
- Occupational Therapy Intervention /Sensory Integration Evaluation.
- Tests/reports given orally. Waive time limits on tests.
- Shorten assignments.
- Verify all homework assignments to make sure they were copied accurately.
- Standardized tests answers written directly in the test booklet and transferred onto answer sheet by teacher or assistant.
- Provide graph paper to help line up math problems or allow child to turn paper sideways.
- Do not penalize students for poor handwriting. Provide alternatives for doing tests, assignments, etc. (orally, taped).
- Do not penalize for spelling errors. Encourage the use of spell check.
- Provide class notes rather than having the student copy from the chalkboard or overhead.

For Obsessive Compulsive Symptoms

Obsessions and Compulsions can take so many forms that it is difficult to give a few pat answers to the problem. You must first assess the nature of the obsessions and brainstorm possible solutions. Here are some examples:

- A student with an obsession to count words in every line that she reads was provided with books on tape.
- A student with a germ obsession is encouraged to carry Purell in his pocket to wash his hands when needed.
- A student who needs to have a perfectly sharpened pencil to write was given a mechanical pencil.

- A student with a symmetry obsession who needs to erase his work over and over because it doesn't look quite right was allowed to use a computer for his work to alleviate the problem.
- Allow transition time between activities for students with TS and BE
CREATIVE!!!!!!

For Short Fuse Difficulties

Children with TS and associated disorders may easily experience frustration, overstimulation, and increased anxiety. Their most difficult areas are crowded hallways, the cafeteria, the school bus and the playground. They do not function well in an unstructured, disorganized classroom. They live daily with a disorder that never allows them to be still. They have difficulty transitioning from one activity to another. A large majority of these children also have sensory defensiveness. Any or all of their senses can become quickly overloaded causing them to be easily "set off". Here are some helpful interventions:

- Allow the child to leave the classroom 2 to 3 minutes early to avoid crowded hallways.
- Have a teacher aide nearby in the cafeteria to prevent confrontations. An alternative eating site with a friend is ideal.
- Seat the child up front on the school bus and educate the bus driver.
- Make sure that the child is in the classroom of a structured, but flexible teacher.
- Help the child learn to remove him/herself from the room before a situation escalates out of control.

For ADHD Symptoms

- Preferential seating in the classroom; up front on the side is ideal where the teacher can assist the child in staying on task. The center front is often embarrassing for the child with obvious tics.
- Provide a quiet place to work in the classroom. A headset with instrumental music might help block out distractions.
- Allow for freedom of movement. (A quick trip to the bathroom, drinking fountain, a classroom task).
- Structured, but flexible classrooms are the best setting for the child with ADHD. Change tasks frequently.
- Establish a hand gesture as a reminder to refocus and get back on task.
- Break down assignments. Give one paper at a time rather than several. Break down all long range assignments and projects into shorter more manageable parts; e.g., Part 1 may be due in 2 days rather than the entire project in 3 weeks.
- Reduce the length of homework assignments. Quality, not quantity is the important thing.
- Provide a daily assignment sheet to be filled out by the student and verified by the teacher for accuracy. The parent could then check to make sure that all the work is accomplished. Assist with homework prioritizing and management.

- Allow student to leave their last class a little early to pack up and organize his materials. This will not only give the student a little more time but also allow him to be at his lockers without the distractions of a crowded hallway.
- Provide an extra set of textbooks for home. Color code textbooks & folders. A blue folder goes with a blue science book.
- Do not penalize students who forget or lose basic classroom supplies. Keep a supply of paper, pens, pencils to lend. Parents could also supply. If you're worried about getting your supplies back, take something in ransom, e.g., a shoe.

REMEMBER that children with TS do not want to be out of control. They may not always know how to avoid situations that cause this to happen. Always keep in mind that this is an expression of a neurological impairment and not necessarily bad behavior.

MEDICATIONS for TS have side effects which may affect performance and behavior in school. Use the school nurse and the parents as resources to keep informed about the medications the child is taking and what may result in the classroom.

(2nd Edition)

by Susan Conners, M. Ed.

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Burlington, Vermont.

Advocating for Your Child: 25 Tips for Parents by David Fassler, M.D.

According to the Surgeon General, 1 child in 5 will experience significant problems due to a psychiatric disorder. The good news is that we can help many, if not most, of these youngsters. The real tragedy is that so few, less than 1 in 3, are receiving the comprehensive treatment they really need.

Children and adolescents with emotional and behavioral problems deserve access to the best possible mental health care. Unfortunately, such services are often difficult to obtain. Parents can help by being informed, involved and persistent advocates on behalf of their children.

The following outline offers specific tips and suggestions which parents may find useful in such advocacy efforts:

1. Get a comprehensive evaluation. Child psychiatric disorders are complex and confusing. A full assessment will often involve several visits. Effective treatment depends on a careful and accurate diagnosis.
2. Insist on the best. Talk to physicians, therapists, guidance counselors and other parents. Find out who in your community has the most experience and expertise in evaluating and treating your child's particular condition. Check the clinician's credentials carefully. Are they appropriately licensed or certified in your state? If he or she is a physician, are they "Board Certified"? Push schools, insurance companies and state agencies to provide the most appropriate and best possible services, not merely services which are deemed sufficient or adequate.
3. Ask lots of questions about any diagnosis or proposed treatment. Encourage your child to ask any questions he or she may have, as well. Remember that no one has all the answers, and that there are few simple solutions for complex child psychiatric disorders. In addition, all treatments have both risks and benefits. Make sure you and your child understand the full range of treatment options available so you can make a truly informed decision.
4. Insist on care which is "family centered" and which builds on your child's strengths. Ask about specific goals and objectives. How will you know if treatment is helping? If your child's problems persist or worsen, what options and alternatives are available?
5. Ask about comprehensive "wrap around" or individualized services, geared specifically to the needs of your child and family. Are such services available in your state or community? If not, why not?

6. Be prepared. One of the most important things you can do to help your child is to keep all information, including past consultation and treatment reports, in an organized place. Insist on receiving your own copies of all evaluations. Records can easily be misplaced, delayed or even destroyed. Maintaining your own file with all relevant information can help avoid unnecessary duplication of previous treatment efforts.
7. Feel free to seek a second opinion. Any responsible mental health professional will be glad to help with referrals or by sharing information. If you have any questions at all about your child's diagnosis or the proposed course of treatment, by all means, arrange an independent consultation with another clinician.
8. Help your child learn about their condition. Use books, pamphlets and the Internet. Make sure the information is age-appropriate. Answer questions with honest, accurate and consistent information, but don't overload children with more detail than they need or want.
9. Learn the details of your insurance policy, and learn about the laws governing insurance in your state. For example, in some states, insurance companies must provide access to a specialist, such as a child and adolescent psychiatrist, within a certain distance from your home. If no such specialist is available as part of the company's "network", you may be able to receive treatment from a provider of your choice, with the insurance company responsible for full payment.
10. Work with the schools. Insist on access to appropriate mental health consultation services. Suggest inservice training programs to enhance awareness about child psychiatric disorders. Request copies of your child's educational records, including the results of any formal testing or other evaluations. Ask to be included in any and all school meetings held to discuss your child.
11. Learn about the reimbursement and funding systems in your state. The more you know, the better you can advocate on behalf of your child. How does Medicaid work? Which services are covered and which are excluded? Is there a "waiver program" which allows increased flexibility based on the specific needs of children and families? Is your child eligible? If not, why not? What other sources of funding are potentially available?
12. Get to know the state insurance commissioner and healthcare "ombudsperson" or consumer representative. Ask them to attend regular meetings with parent groups. Let them know about your experiences.
13. Use a lawyer, if necessary. Learn about the local legal resources. Find out which lawyers in your community are familiar with educational and mental health issues. Talk to your local Protection and Advocacy agency or American Civil Liberties Union for suggestions. Call the State Bar Association. Talk to other parents who are lawyers or who have used lawyers. Consider a legal consultation to make sure you are pursuing all appropriate avenues and options regarding services for your child.
14. Become politically active. Meet with state senators and representatives. Question candidates about their positions on access to necessary and appropriate mental

health services for children and families. Testify at hearings on state legislation and budgets. Legislators are more likely to be influenced and persuaded by personal stories than by data, statistics or the opinions of professionals.

15. Build coalitions and work with local advocacy and parent organizations such as NAMI, NMHA and the Federation of Families. Develop and publicize a common "Agenda for Children's Mental Health".
16. Teach children about advocacy. Invite them to become involved in advocacy activities, where appropriate, but don't force them to participate.
17. Develop a legislative strategy. If your state does not yet have parity legislation, put this at the top of the agenda. Other "family protection" initiatives include:
 - access to an independent panel to review and potentially reverse insurance company denials
 - consumer representation on community mental health center boards
 - adequate network provisions, which mandate timely and appropriate access to specialists
 - adequate funding for school and community based mental health services.
18. Seek bipartisan support. Mental illness effects families of all political persuasions. Building a broad base of support has been a key to successful legislative initiatives, both at the State and Federal levels.
19. Fight stigma. Develop an ongoing local education campaign that reiterates the key messages:
 - child psychiatric disorders are very real illnesses
 - they effect lots of kids and adolescents
 - fortunately, they are also quite treatable, especially if treatment begins early and is individualized to the needs of each child and family.
20. Become involved with medical education. Meet with local medical students and residents. Sensitize them to the issues and challenges families face when caring for a child with emotional and behavioral problems.
21. Use the media. Write letters to the editor and/or op-ed pieces on child mental health issues. Meet with local reporters covering health care topics. Suggest story ideas to local TV stations.
22. Work with local professional organizations. Psychiatrists, psychologists, social workers, psychiatric nurses, and mental health counselors are natural allies with a common advocacy agenda. Coordinate efforts on issues such as parity, funding for mental health services, managed care oversight, etc. Professional organizations may also have access to resources, including funds for lobbying and/or public education initiatives, from their national associations.

23. Talk to other parents. Seek out and join local parent support groups. If none exist, consider starting one. Develop an email "listserv" to facilitate communication. Circulate articles, information and suggestions about local resources.
24. Attend regional and national conferences of parent and advocacy organizations. Such meetings provide information, ideas, camaraderie and support. Sharing experiences with other parents is both helpful and empowering.
25. Don't give up. Aim for and celebrate incremental victories and accomplishments. Remember, advocacy is an ongoing process!

There's no right or wrong way to be an advocate for your child. Advocacy efforts and initiatives should be individualized to your state, community and the particular issues, circumstances and needs within your family. Advocacy is also hard work. Even when people want to help, and are willing to listen, it takes lots of time and energy to change the system. But when it works, and it often does, the outcome is clearly worthwhile. You really can make a difference, both for your own child, and ultimately for all children who need and deserve access to appropriate and effective mental health treatment services.

Resources

The following organizations are excellent resources regarding advocacy on behalf of children's mental health:

American Academy of Child and Adolescent Psychiatry
3615 Wisconsin Avenue, NW
Washington, DC 20016
(202) 966-7300
www.aacap.org

American Psychiatric Association/Division of Public Affairs
1400 K Street, NW
Washington, DC 20005
(202) 682-6140
www.psych.org

Federation of Families for Children's Mental Health
1101 King Street, Suite 420
Alexandria, VA 22314
(703) 684-7710
www.ffcmh.org

National Alliance for the Mentally Ill
Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-3042
(703) 524-7600
www.nami.org

National Mental Health Association

1021 Prince Street
Alexandria, VA 22314-2971
1-800-969-6642
www.nmha.org

The Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202) 628-8787
www.childrensdefense.org

Bazon Center for Mental Health Law
1101 15th Street NW, Suite 1212
Washington, DC 20005-5002
(202) 467-5730
www.bazon.org

Childhood and Adolescent Bipolar Foundation
1187 Wilmette Avenue
P.M.B. #331
Wilmette, IL 60091
(847) 256-8525
www.bpkids.org

Children and Adults with
Attention-Deficit/Hyperactivity Disorder
(CHADD)
8181 Professional Place, Suite 201,
Landover, MD 20785 CHADD
1-800-233-4050, (301) 306-7070
www.chadd.org
Juvenile Bipolar Research Foundation
49 S. Quaker Road
Pawling, NY 12564
(203) 226-2216
www.bpchildresearch.org

Depression and Bipolar Support Alliance (DBSA)
730 N. Franklin Street, Suite 501
Chicago, IL 60610
1-800-826-3632
(312) 642-0049
www.ndmda.org

Depression and Related Affective Disorders Association (DRADA)
Meyer 3-181, 600 North Wolfe Street
Baltimore, MD 21287-7381
(410) 955-4647
www.drada.org

Dr. Fassler is a Board Certified Child and Adolescent Psychiatrist practicing in Burlington, Vermont. He is a Clinical Associate Professor in the Department of Psychiatry at the University of Vermont College of Medicine. Dr. Fassler is also a Trustee of the American Psychiatric Association (www.psych.org), a Fellow of the American Academy of Child and Adolescent Psychiatry (www.aacap.org), and a member of the Board of the Federation of Families for Children's Mental Health (www.ffcmh.org).

Resources

Organizations

Tourette Syndrome Association
42-40 Bell Boulevard
Bayside, NY 11361-2861
(800) 237-0717
(718) 224-2999
E-Mail: Tourette@ix.netcom.com
Website: <http://tsa/mgh.harvard.edu/>
State and local chapters provide national information, advocacy, research and support.

Council for Exceptional Children
1101 North Glebe Road
Arlington, Virginia 22201
1-(800) 328-0272
E-Mail: ericec@cec.sped.org
Website: <http://ericec.org>
Provides publications for educators. Can also provide referral to ERIC (Educational Resource Information Center)

Books

FAMILY ISSUES:

Tourette Syndrome Foundation of Canada: *Understanding Tourette Syndrome: A Handbook for Families*. <http://www.tourette.ca/products.html>.

Waltz, M. (2001). *Tourette's Syndrome Patient Centered Guides*. O'Reilly & Associates.
<http://www.amazon.com/exec/obidos/ASIN/0596500076/touretsyndroplus>.

SCHOOL-RELATED:

Byalick M. (2002) *QUIT IT*.
<http://www.amazon.com/exec/obidos/tg/detail/-/0385729979/touretsyndroplus> Delacorte Press.

Dornbush MP, Pruitt SK. (1995). *Teaching the Tiger*.
<http://www.amazon.com/exec/obidos/ASIN/1878267345/touretsyndroplus>.
Hope Press.

Krueger, T. (2001). *Taking Tourette Syndrome to School*.
<http://www.amazon.com/exec/obidos/ASIN/1891383124/touretsyndroplus>.
Jayjo Books.

RECENT BOOKS FOR PROFESSIONALS:

Cohen DJ, Jankovic J, & Goetz CG (eds.). (2001). *Advances in Neurology: Tourette Syndrome*.
<http://www.amazon.com/exec/obidos/ASIN/0781724058/touretsyndroplus>

Lippincott Williams & Wilkins.

Kushner HI. (1999). *A Cursing Brain? The Histories of Tourette Syndrome*.
<http://www.amazon.com/exec/obidos/tg/detail/-/0674003861/touretsyndroplus>.
Harvard University Press. Leckman JF, & Cohen DJ (eds.).

Leckman, J. & Cohen, D. (1999). *Tourette's Syndrome--Tics, Obsessions, Compulsions: Developmental Psychopathology and Clinical Care*.
<http://www.amazon.com/exec/obidos/ASIN/0471113751/touretsyndroplus>.
John Wiley & Sons.

Woods DW, & Miltenberger RG (eds.). (2001) *Tic Disorders, Trichotillomania, and Other Repetitive Behavior Disorders: Behavioral Approaches to Analysis and Treatment*.
<http://www.amazon.com/exec/obidos/ASIN/0792373197/touretsyndroplus>
Or Kluwer, <http://www.wkap.nl/prod/b/0-7923-7319-7?a=1>.

Haerie, T. *Children with Tourette Syndrome: A Parent's Guide*.

Johnson Hammer, S. *Raising Joshua: One Mother's Account of the Challenges Parenting a Child With Tourette Syndrome*. (956) 682-9310.

Dornbush, M. (1995). *Teaching the Tiger: A Handbook for Individuals Involved in the Education of students with Attention Deficit Disorder, Tourette Syndrome or Obsessive Compulsive Disorder*. Hope Press. Full of practical step-by-step positive interventions that parents and professionals can use to help children with ADHD, TS and OCD be successful.

Videos

Tourette Syndrome: The Parents Perspective - Diplomacy in Action. Features E. Collins Ph.D. and R. Fisher-Collins, M.Ed. Providing guidance to Tourette Syndrome families on school advocacy issues. Concrete ideas to insure the success of the child's school experience. 40 minutes. Can be ordered through the Tourette Syndrome Assn.

The national <http://tsa-usa.org> sells a number of videos. In addition to what they have, you might also want to consider:

Be My Friend. Available from the <http://www.mn-tsa.com> of TSA. Can be used for peer education programs for elementary school-age children.

Twitch and Shout. A documentary by Laurel Chiten on TS that aired on PBS. Can be ordered from http://www.newday.com/films/Twitch_and_Shout.html.

Bending the Rules: a Guide for Parents of Troubled Children. Michael McDonald Productions, 1996. 60 min. You can read the description of it and order it from the <http://www.tourettesyndrome.org/page11.html>

ABC's 20/20 also did a segment in January, 1998 on how teenagers with TS cope with it. The transcript and ordering information are available online at <http://www.abc.com>. Jim Eisenreich has a video, too. Jim is a national spokesperson and a role model for many children with TS.

John's Not Mad is a UK film about Tourette Syndrome. It shows a teenager with severe tics (including spitting and coprolalia), and has interviews with his mother and teachers; available from <http://www.filmakers.com>, but note that it is in UK format and not compatible with standard VHS format.

Danya International has produced a video for peer education purposes. See their web site at <http://www.danya.com/index2.htm> for info on the video.

Web sites

Federation of families for Children's Mental Health

www.ffcmh.org

1101 King Street, Suite 420

Alexandria, VA 22314

(703) 684-7710

E-Mail: ffcmh@ffcmh.org

Web: www.ffcmh.org

A national parent-run, non-profit organization focused on the needs of children and youth with emotional, behavioral, or mental disorders and their families.

National Information Center for Children and Youth with Disabilities

<http://www.kidsource.com/NICHY>:

P.O. Box 1492

Washington, DC 20013

(800) 695-0285

Published free, fact-filled newsletters, arranges workshops, advises parents on the laws entitling children with disabilities to special education and other resources.



PLACE
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HERE

Vermont Family Network
600 Blair Park Road, Suite 240
Williston, VT 05495-7549

CITY, STATE, ZIP:

ADDRESS:

NAME:

If you'd like to learn more about VFN's materials, please visit our website at www.VermontFamilyNetwork.org or write your name and address below:

Dear Reader,

Vermont Family Network (VFN) strives to make each of its publications clear, correct, and complete. Please help us by answering a few questions.

1. *Which publication* are you evaluating? _____ Tourette's Syndrome _____

2. Please rate this publication:

	EXCELLENT	GOOD	FAIR	POOR
a. for <i>completeness</i> of information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. for <i>clarity</i> (ease of use)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. for <i>accuracy</i> of information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. <i>overall</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. If you *found any incorrect information* in this publication, please specify the page(s) and correction(s) to be made. _____

4. If you felt *information was left out* of this publication, please specify the page(s) and addition(s) to be made. _____

5. If you found *anything hard to understand* in this publication, please specify the page(s) and confusing passage(s). _____

6. If any part *of* this publication was *especially good* at helping you understand the topic, please specify the page(s) and passage(s). _____

7. How do you *plan to use* the information you've obtained from this publication? _____

8. Finally, please check *all* of the following that apply to you:

<input type="checkbox"/> parent or guardian	<input type="checkbox"/> surrogate or foster parent
<input type="checkbox"/> relative, friend or advocate	<input type="checkbox"/> educator
<input type="checkbox"/> individual with a disability	<input type="checkbox"/> service provider (<i>agency</i>) _____
<input type="checkbox"/> other (<i>please specify</i>) _____	_____

Thank you for taking the time to let us know how we might improve our materials.