

TOURETTE SYNDROME ASSOCIATION

CHAPTER PROGRAM MANUAL

VOLUME II

I. SERVICE PROGRAMS FOR TSA CHAPTERS AND SUPPORT GROUPS

II. THE NATIONAL TSA RESEARCH PROGRAM

TOURETTE SYNDROME ASSOCIATION CHAPTER
PROGRAM MANUAL II

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II. THE NATIONAL TSA RESEARCH PROGRAM

I. SERVICE PROGRAMS FOR TSA CHAPTERS AND SUPPORT GROUPS;

A. INFORMATION AND REFERRAL FOR PEOPLE WITH TS AND THEIR FAMILIES

1. HANDLING TOURETTE SYNDROME INQUIRIES

Advance Preparation

The wide geographical areas served by TSA chapters often make personal exchange of information difficult between chapter workers and clients concerned with TS. Many TS families who need to talk with someone knowledgeable and sympathetic about TS count on speaking with chapter leaders by phone. Telephone work, therefore, is the cornerstone of TSA chapter referral services. In responding to these client calls the chapter volunteer provides valuable information about TS and perhaps the first support the caller has received in dealing with TS.

Chapter representatives who undertake to respond to inquiries about TS must be knowledgeable and well prepared if they are to provide effective service. They must:

- Know the facts about TS: the symptoms of TS, the criteria for diagnosis, and the side effects of common medications.
- Know resources which are available to help those concerned with TS:
 - physicians and psychotherapists familiar with TS;
 - state and county agencies providing services to people with TS;
 - sources of financial aid.
- Be familiar with educational processes:
 - how schools can help children with TS; and
 - what children are entitled to under the law.
- Keep a log of inquiries: It is important to keep records of all inquiries to the chapter, both telephone calls and letters, on a standard log form. A sample Chapter Inquiry Log Form is Item (a) in the Appendix to this Section.

There are several reasons for logging inquiries and using a standard form:

- A standard log form assures that the volunteer asks appropriate questions to elicit key information useful both in responding to the initial inquiry and in following up.

- Information from the logs about clients' needs can help the chapter develop activities in response to those needs:
 - chapter meeting programs;
 - support groups;
 - workshops;
 - education programs for professionals;
 - education programs for the general public.

- If the chapter applies for grants or other sources of funds, logs will provide data about the need for funding.

Responding to Tourette Syndrome Inquiries

The relatively impersonal qualities associated with knowing the facts about TS and keeping a log of inquiries will not, however, be enough to provide a warm and satisfying response to the individual who calls the chapter for help. The chapter volunteer must also:

- Know how to listen:

Quietly and non-judgmentally, perhaps occasionally summarizing and rephrasing the ideas and feelings expressed.

Listening sounds easy, but it requires great attentiveness. The volunteer must be able to assess what the problem is and what the needs are, and to sense the best time to shift gears from the relatively passive role of listening to the more active one of responding and referring.

- Know how to respond:

The immediate needs of a caller will usually be for reassurance, support, and information about TS.

Families with a newly diagnosed member often phone the local TSA chapter with questions--questions they neglected to ask their doctor, or ones they did ask but must ask again because they were too upset to fully comprehend the doctor's answer. Sometimes the family feels that the physician who diagnosed a person with TS did not fully explain the disorder during the limited time of the office visit. And sometimes the family member was afraid to ask the doctor some questions (i.e., is TS a fatal condition?) and needed time to build the courage to ask.

When you receive an initial phone call from a family concerned with TS it is important that you share with the caller your own relationship with a person with TS. He/she will be comforted to know you have had

experience with TS and are personally familiar with problems related to the disorder.

Remember, in the early days after a diagnosis many families feel a NEED TO TALK with someone about TS. Many calls from individuals or parents who have just received a diagnosis of Tourette Syndrome carry with them highly charged feelings. People react to a diagnosis of Tourette Syndrome in varying ways from action--spending a week in the local medical library reading everything they can get their hands on--to a range of emotions: guilt, anger, denial and fear.

- GUILT on the part of parents who misunderstood and misinterpreted their child's tics as willful misbehavior and punished the child accordingly, or guilt on the part of a parent who recognizes him/herself to be the genetic carrier.
- ANGER directed toward professionals (doctors, teachers) who failed to diagnose or identify the TS symptoms earlier, or toward family members who may have mistreated the child, and inwardly directed anger at themselves for their own perceived insensitivity.
- DENIAL by questioning the accuracy of the diagnosis and/or ignoring the impact that TS may be having on the child's life, or attributing the symptoms to other causes. The lack of a conclusive clinical test to confirm a TS diagnosis (X-ray or CAT scan) makes denial easier.
- FEAR about what the future holds--what course the TS symptoms will take and what impact having the disorder will have on education, career or marriage.
- RELIEF at finally having a name and explanation for the TS symptoms, at learning about available medication and at discovering a support network. Before getting an accurate diagnosis, individuals and families frequently have spent much time and money going down dark alleys that led nowhere. They are now relieved to have both a diagnosis and a connection with a network of people familiar with the disorder.

The first thing the chapter volunteer must do is simply let the individual tell his/her story even though you have heard it countless times before. Remember the sense of relief you felt when you first spoke to another parent of a child with TS. The response will often be, "So we are not the only family struggling with this." Just connecting with another person or family in the same situation can be truly uplifting. This support is one of the paramount services chapters can offer.

The family that has been able to have an unhurried discussion with a knowledgeable volunteer will always remember and appreciate the service offered when they were in need. Taking the time to talk with these families will foster their loyalty to your local TSA chapter and their support of it.

In talking with people about TS, it is helpful if you are sensitive about the choice of words you use in describing the condition. Considerate use of everyday language can do much to foster a positive self-image in people with TS. An individual with TS is just that, a person who has Tourette Syndrome. But to call him/her a "Touretter" is, in effect, to define that person by the condition. To say that a person is "crippled by TS," "afflicted with TS," or a "victim of TS" can create the impression that a person with TS is helpless or pitiful.

Sometimes the word "patient" must be used in a medical context, i.e., a letter to a doctor, and sometimes the words "afflicted" and "sufferer" can be effective in fund raising literature but, for the most part, it will be helpful to people with TS and their families if you avoid using the following words in conversation, newsletters, and speeches.

| | | |
|-----------|----------|------------|
| Afflicted | Patient | Touretter |
| Crippled | Sufferer | Tourettism |
| Disease | Ticquer | Victim |

Making a Referral

After receiving the answers to questions, the longer-term needs of callers may be for referral--to a knowledgeable local physician, psychologist, or other professional, or to sources of educational or financial assistance. When you give responses or make referrals concerning Tourette Syndrome, remember to follow these guidelines:

- In making verbal referrals:
 - Do not give medical advice or appear to be making a diagnosis.
 - Do not directly recommend one physician over another.
 - Never criticize a professional when making recommendations.
- When you provide a written referral, it should always carry a disclaimer similar to the following one which is used by the National TSA Information and Referral Service:

"The following service providers have stated an interest in assisting people with TS. These names are given for informational purposes only. TSA and its affiliates assume no liability whatsoever for any service mentioned. We encourage you to investigate all referrals to better assess their suitability for your particular needs."

- If you sense that the caller is uneasy with the professional attention or advice he/she has received, you might suggest, "Perhaps you would like a second opinion." This opens up the possibility of the caller's consulting another professional without your having passed judgement on the original professional contact.
- To help the caller understand more about Tourette Syndrome, you should always send a TSA catalog, offer to provide TS literature, and refer the family to national TSA for more information.
- Invite the caller to a support group meeting or to the next general chapter meeting. Suggest ways the caller can become involved in the chapter. Many times it is good therapy for the parents to do something specific in order to feel they are finally taking positive action to help their child.
- Finally, it is also important for callers to understand that the person who answers the phone is not there to provide ongoing support. That is the function of the chapter support group.

Some calls may be crisis calls, characterized by a high degree of emotion. For guidance in handling crisis calls, refer to Section I. B., "Responding to Crisis Calls," in this Program Manual.

Dividing Responsibility for Responding to Inquiries

Some chapters have one person who has the time, interest and ability to answer all inquiries that come to the chapter. When there is no such individual in the chapter (or to keep that individual from burning out) calls can be divided among several members if incoming calls are picked up by an answering machine. Members can rotate responsibility for calling the machine to pick up messages. Some parent training organizations allow member groups to use phone lines at their office for this purpose, if the member group provides the answering machine.

When responsibility for responding to inquiries is shared, it is especially important to use a Inquiry Call Log Form, referred to above, to record inquiries. The chapter should provide each chapter volunteer who responds to inquiries with a kit containing:

- Inquiry Call Log Forms,
- Referral information, and
- TSA materials to mail to inquirers.

2. DEVELOPING A CHAPTER REFERRAL INFORMATION FILE

The Chapter Referral Information Chair

To meet the referral needs of chapter members, the chapter President should appoint a Referral Information Chair whose duty will be to collect, organize and maintain up-to-date information about:

- Individuals--physicians, psychologists, social workers, tutors, etc., and
- Organizations--federal, state, and local agencies and not-for-profit organizations which provide services to people with TS.

Collecting Referral Information

The following essential referral information is provided in this manual:

- National TSA Physician Referral List for Chapter's state (Item (b) in the Appendix of this Section of the Manual).* This gives name, address, telephone number and medical specialty of physician who have indicated they are experienced in diagnosing and treating TS.
- National TSA Allied Professional Referral List for Chapter's State,(Item (c) in the Appendix of this Section of the Manual).* This gives name, address, telephone number and professional specialty.
- State Developmental Disabilities Planning Councils, listed by state in Item (d) in the Appendix of this Section of the Manual.**
- Parent Training Organizations, listed by state in Item (e) in the Appendix of this Section of the Manual.**

In addition, the Chapter Referral Resource Chair should undertake to develop a wide list of other referral sources. To collect and organize this material it is helpful to have a standard form to ensure that all relevant information about agencies or individuals to which TS clients can be referred is gathered. Item (f) of the Appendix of this Section of the Manual is a Sample Information Form designed to guide the chapter in collection of this information.

Additional referral information can also be gathered through:

- Contact with other TSA chapters about their sources of service information.
- Chapter-area telephone directories which can provide leads on local service providers.
- Organizations, such as United Way, whose services are not specifically directed toward disabilities can provide information about general services (financial assistance; crisis intervention phone lines) and about resource directories.

* Updated lists are regularly sent to chapter presidents. Since these basic tools for your referral kit are compiled by TSA Advisory Boards, they may not be amended by the chapter.

** These agencies serve special needs children and can provide information about state agencies and the services they offer; state information and referral services specializing in assisting people with disabilities and resource directories of services in the state. Updated lists can be obtained through the TSA Information and Referral Service.

- Service providers on the chapter referral list can, themselves, be sources of information about others who could serve people with TS. For example, a parent training organization could supply the names of school advocates who have been trained in its classes.
- An ongoing exchange of service information between the chapter and National TSA's Information and Referral Service.

Organizing and Updating Referral Information

A loose-leaf notebook of resources, which can be copied for all chapter members who provide referrals, is useful. If the chapter has access to a word processor for storing and printing listings, updating is much easier. If computer capability is available, a system can be created whereby resource entries can be called up by specific criteria such as geographical location, services provided, ages of clients served, etc.

It is important to keep the chapter listings up-to-date. Contact people and hours change often, and agencies may close or move. If there are state disability information and referral sources that keep their listings current, the chapter may choose to use that referral system when possible and, therefore, keep fewer separate listings in its own referral data file.

However, it is valuable to keep a listing of resources that are known to have successfully helped people with TS, since other information and referral resources usually will not know who has specific TS experience.

3. THE TSA INFORMATION AND REFERRAL SERVICES DEPARTMENT

Public information about Tourette Syndrome and the Tourette Syndrome Association is a major part of Information and Referral Services (I&RS) Department responsibilities. Every year TSA contacts thousands of health care providers, insurance companies, educators, educational administrators, allied professionals, law enforcement agencies, diagnostic centers, family and primary care specialists, schools and school districts, clinics and hospitals, independent living facilities and many other related local, state and federal agencies. The educational sphere of the I&RS department often includes marketing projects with these agencies and professionals to advertise TSA's publications and services. I&RS has another autonomous responsibility to maintain and coordinate medical and scientific programs such as national TSA Brain Bank registration. All the above involves the I&RS department in an active process of public relations and communications.

To better respond to questions and concerns from all over the country on issues ranging from education to SSI, national TSA's I&RS department has developed a database of national resources, services and supports for people with TS. The

National TSA Resources List which summarizes this data base is given in Item (g) of the Appendix of this Section of the Manual. This database is maintained and continuously updated by the I&RS department. A major focus of the I&RS department is to have information about state of the art resources around the nation. Our goal is to respond to the thousands of requests for assistance we receive every month. Another objective is to share these resources with chapters and support groups and to establish a communication loop between national TSA and chapters.

TSA will regularly send chapters information about data in its I&RS databank for the chapter area. National TSA asks that chapters regularly update and augment the national TSA data by submitting names, addresses, phone numbers and specialties of local service providers to the national I&RS. A Form for Chapter Suggestions of Allied Professionals for Referral by TSA is included in Item (h) of the Appendix of this Section of the Manual. National I&RS will investigate qualifications of those professionals and decide whether or not they should be added to the TSA Allied Professional Referral List.

Appendix A, Item (a)
TSA CHAPTER INQUIRY LOG

Date _____

Inquirer's Name: _____

Street Address: _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Work Phone: _____

FAX: _____ E-Mail: _____

Referred
by: _____

Person with TS: _____

Name: _____ Date of Birth: _____

Diagnosed? Yes [] No [] If Yes, Date of Diagnosis _____

Relationship to Caller: _____

Information/help needed:

Information/help provided:

Date request completed:_____Completed by_____

Comments:

Approval received from caller to send name to National? [] Yes [] No

Date name sent to National, if approved._____

**ITEMS FOR APPENDIX A NOT INCLUDED IN THIS PACKET;
THESE MUST BE PROVIDED BY THE TSA OFFICE**

- (b) Physicians Referral List for Chapter State
- (c) Allied Professional Referral List for Chapter State
- (d) State Developmental Disabilities Planning Councils, listed by State.
- (e) Parent Training Organizations, listed by state.

Appendix A, Item (f)
SAMPLE INFORMATION FORM
AGENCIES AND INDIVIDUALS THAT PROVIDE SERVICE TO PEOPLE WITH TS

Date Entered: _____ Date Revised: _____

SERVICE PROVIDER:

Name: _____

Address: Street _____

City: _____ State: _____ Zipcode: _____

Phone 1: _____ Phone 2: _____

TDD: _____ FAX: _____ E-mail _____

TYPE OF SERVICE:

- | | |
|-------------------------------------|---|
| <input type="checkbox"/> Advocacy | <input type="checkbox"/> Legal |
| <input type="checkbox"/> Counseling | <input type="checkbox"/> Medical - Specialty: _____ |
| <input type="checkbox"/> Education | <input type="checkbox"/> Social Service – Type: _____ |
| <input type="checkbox"/> Employment | <input type="checkbox"/> Psychological |
| <input type="checkbox"/> Housing | <input type="checkbox"/> Vocational Rehabilitation |
| <input type="checkbox"/> Insurance | <input type="checkbox"/> Other: _____ |

SOURCE OF INFORMATION:

CHAPTER EXPERIENCE WITH THIS REFERRAL:

COMMENTS:

Appendix A, Item (g)
NATIONAL TSA RESOURCES LIST

GENERAL

- Crisis hotlines.
- Web site page - www.tsa-usa.org
- Independent living centers.
- SSI and SSDI information and list of SSA offices.
- List of TS specialists: lawyers and advocates, social workers, psychologists, learning disabilities specialists, physical therapists, speech and language pathologists specializing in neurological disorders.

MEDICAL

- Physician referral list.
- Residential facilities.
- Psychiatric clinics.
- Facilities for emotionally disturbed.
- Facilities for orthopedic and neurological disabilities.

LEGAL

- Legal referral services.
- Pro bono services (free of charge)
- Disabilities protection and advocacy centers (low cost or free of charge).
- Parents training and information projects.
- Employment rights ADA booklets.

FRIENDS AND FAMILY

- “Friends can make a difference” program.
- TSA’s crisis hot-line.
- Parents training and information project (same as legal).
- Web site page – www.tsa-usa.org

EDUCATIONAL

- List of private schools with description of special programs.
- Vocational and Rehabilitation Service Agencies.
- Learning disabilities associations.
- Parents training and information projects (same as legal).

EMPLOYMENT

- Vocational Rehabilitation Service Agencies (same as educational).
- ADA booklets (same as legal).

Appendix A, Item (h)
FORM FOR CHAPTER SUGGESTIONS
OF ALLIED PROFESSIONALS FOR REFERRAL BY TSA

The _____ Chapter would like to suggest

Name: _____

Address: Street: _____

City: _____ State _____ Zip _____

Phone: _____ FAX: _____ E-mail: _____

for consideration for being added to the TSA Allied Professionals Referral List.

Area of professional practice:

- Attorney
- Educational Consultant
- Nurse
- Occupational Therapist
- Psychologist/Counselor
- Social Worker
- Speech Therapist
- Other

Comments:

Submitted by: _____

Chapter: _____

Chapter position: _____ Date: _____

Send to: Executive Vice President: TSA Information & Referral Department
40-42 Bell Blvd., Bayside, NY 11361

B. RESPONDING TO CRISIS CALLS

From time to time the chapter volunteer who mans the chapter telephone may be called on to respond to a crisis call. Crisis calls can come from:

- a parent with a newly diagnosed child
- an adult who has just been diagnosed to have TS
- a person with new symptoms or medication side effects
- a parent having trouble with the school system
- a person with TS having employment problems
- a family involved in a legal battle
- a person contemplating suicide

Crises are characterized by feelings of helplessness and chaos, and by a sense of urgency. The person who receives crisis calls must guard against becoming overwhelmed by the caller's feelings. It is important to remain calm while helping the caller sort out and prioritize the problems and to help focus on the immediate need.

The person responding to a crisis call should perform three services: to listen, to calm the caller, and to refer.

LISTENING

Listening is often the greatest help we can offer someone in crisis. Many times it happens that a volunteer will be thanked for his invaluable advice at the close of a conversation even though the volunteer has only listened and responded with an occasional "I see" or "uh-huh" as the person in crisis has described his/her situation at some length.

Listening is not hard, but it's not that easy either. The listener must be patient and resist the impulse to jump in with premature solutions and advice.

CALMING

The first calming response is to assure the caller that he/she has taken a positive step by calling you, and that you will do your best to refer him/her to a source of help. Then you must elicit pertinent information from the caller to determine the most appropriate assistance, and to be able to inform the caller about TS as it is related to his/her specific problems. While obtaining information from the caller and explaining more about TS you will also be distracting the caller from his/her immediate anxiety. The information you give about TS may, in itself, reduce anxiety if the anxiety is caused by inaccurate information. In addition, most people who call about TS are greatly relieved to be speaking with someone familiar with the condition. In some cases, the frustration of dealing with people and agencies ignorant about TS may have precipitated the crisis call.

9.

Sometimes listening and calming may be all that is needed. Recently a call came

to TSA from a young man who had been sent home from his job that day because of a flare-up of symptoms. This was the man's first substantial job. Even though his boss had always been sympathetic to his condition and had made no mention of firing him, the young man, nevertheless, feared he would be fired.

The young man had worked himself into an agitated state. The TSA social worker first listened as he described the problem and then assured him that he had reached a source of help knowledgeable about TS. The social worker next asked questions about his symptoms (How severe were they? How severe had they been?). He followed these questions with an explanation of the tendency of TS symptoms to wax and wane and empathized with the frustration that the change in symptoms can cause. By gently engaging the young man in discussion, the social worker was able to shift the focus from anxiety about losing his job to what was really concerning him -- his worsening symptoms -- and, in the process, to increase his understanding of Tourette Syndrome.

In another instance, when a mother called distraught and tearful over the prospects of a bleak future for her young son because he had been diagnosed to have TS, a sympathetic and understanding person was able to temper her intense emotions by gently asking her to tell about her son's symptoms, his progress in school, and his social life. Acknowledging that the child was doing well in school and that his symptoms were mild helped pull her out of her downward spiral of despair.

During the calming phase, the TSA volunteer will usually be asked many questions by the parent or newly diagnosed individual. The medical questions should be referred to a physician, but the responder should feel free to address general questions that stem from anxiety. For example:

- Q. Should my son speak to a therapist?
- A. If he is having a hard time adjusting to the diagnosis, seeing a knowledgeable therapist can be helpful. (This also holds true for the parents themselves.)
- Q. What about medication? I hate the thought of my son's having to take a powerful drug.
- A. There are several medications used in the treatment of TS. Some are stronger than others. This is a question you must take up with your doctor.

To help the caller understand more about Tourette Syndrome, you should always offer to provide initial literature and send a TSA catalog which contains information about additional information available from national TSA. Invite the caller to a support group meeting or to the next general meeting of the chapter. Suggest ways the caller can become involved with the chapter. Many times it is

good therapy for the parents to do something specific in order to feel they are finally taking positive action to help their child. It is also important for callers to understand that the person who answers the phone is not there to provide ongoing support. That is the function of the chapter support group.

It is necessary to complete the listening and calming stages of response before making a referral. The TSA responder needs to have a clear understanding of the problem, and the caller needs to be calm enough to be disposed to accept a referral.

A common mistake a well-intentioned call-handler may make is the "Chicken Little" reaction: allowing the caller's distress to influence the volunteer to the point that he/she, too, thinks the sky is falling. When this happens the call-handler may jump to the referral stage prematurely. In the example of the young man concerned about his job, if referral had been made before it became clear that the real problem was anxiety about exacerbated symptoms, the call-handler might have precipitously referred the young man to an anti-discrimination agency or to a vocational rehabilitation program. Or, in the case of the mother concerned about a newly diagnosed child, if the call-handler had not taken the time to learn that the newly diagnosed boy was doing fine academically, he might have rushed into informing his mother about the IEP process of dealing with school problems.

REFERRAL

To refer callers is to point them in the direction of help. Beyond simply being available to give support, this is the most important service the TSA volunteer can offer. The chapter person who receives client calls should be prepared in advance to provide referrals to individuals who call in crisis. For this you must have readily at hand the names, addresses and telephone numbers of:

- physicians on the TSA referral list
- psychotherapists familiar with TS (or chronic illness or disabilities) for counseling
- psychologists familiar with TS who can provide testing service.
- hospital emergency rooms
- legal services
- educational advocates
- vocational rehabilitation services
- residential alternatives
- emergency hot lines, e.g. suicide and other crisis lines
- local police

A form on which information needed to make referrals in response to crisis calls can be compiled is Item (a) of the Appendix of this Section of the Manual. It can be crucial to have this information at hand in advance in the event of a crisis call.

Information about Suicide Hotlines, by state, is provided in Item (b) of the Appendix of this Section of the Manual. In addition, the information compiled by the chapter using the form Item (f) of Appendix A of this Manual to collect chapter information about agencies and individuals that provide service to people with TS will also provide valuable information in making referrals in response to crisis calls.

Anyone who offers Tourette Syndrome telephone support must realize that, despite your best efforts, there will be some people you cannot help, either because they resist your referrals or because you are genuinely unable to provide a source of help for their problem. Call-handlers may feel guilty when they are unable to be helpful particularly when the caller describes how he/she has been bounced around from one agency to another. In situations like this it is hard not to feel that you, also, are "shunting them off." Nevertheless, it is not helpful to give the crisis caller the impression that you can solve all of their problems when that is not possible. This cannot be over-emphasized. When call-handlers get over-involved in a situation they are not equipped to handle, it can do the client a real disservice and may unwittingly put everyone involved at risk.

If you can accept that there will be a fair number of crises in which you cannot be helpful, and realize that no one can help everyone, you will be in a better position to assist those you are able to help.

THE SUICIDE CALLER

It is likely that you may never receive a call from someone who seems suicidal, but in case you should, it is wise to be prepared beforehand.

It is important to understand that a call from someone in suicidal crisis should be viewed as a cry for help. Suicidal callers are ambivalent about suicide; they say they want to die, but they also want to be helped. It is essential to have thought through the appropriate responses in advance.

- First, always take seriously a caller who may be suicidal. It is better to be overly cautious than to under-react.
- Second, do not assume the responsibility of assessing whether the caller is really suicidal or how suicidal he/she is. Only a trained mental health professional is equipped to determine this.

Therefore, your goal is to refer the caller to appropriate help as soon as possible. In handling a crisis call from someone who may be suicidal, you will by-pass the first two stages (listening and calming) and go directly to the third stage, referral.

If the caller has a psychotherapist or psychologist, try to direct him/her to that professional. If possible, obtain the name, phone number, and present location of the caller and the treating professional. Call that professional and alert him/her about your contact with the caller, and confirm that he/she will handle the crisis. You might also follow up later with another call to the professional to learn that the situation has been handled.

If the caller does not have a therapist, refer him/her to the nearest hospital emergency room--to a psychiatric emergency room, if possible. Call the emergency room to alert staff ahead of time. Again, it may be appropriate to call later to follow up.

If the caller is alone, it is wise to try to obtain the name and phone number of a family member or friend who can be called and asked to be with the caller until help is obtained and the situation is stabilized. It is important for "significant others" to know that the caller is in need of help and that they are needed to help the caller through the crisis.

Another source of help is the suicide hot-line in your area. A list of hot-lines, by state, is appended to this volume of the Chapter Program Manual. Learn about this resource in advance by calling and becoming familiar with the appropriate procedures for referral. If the agency has a positive name, such as "Help Line," it may be appropriate to refer the caller directly. However, if the name of the agency includes the word "suicide" or other terms that might frighten the caller, it would be better for you to make the call to enlist the help of these trained crisis interveners.

If the risk of suicide appears immediate and you cannot convince the caller to contact a hot-line, then the course of action is to call the police. They are trained and are able to respond quickly.

SUMMARY

In handling crisis calls, the objective is to listen, to remain calm, and then to refer the caller to a source of help, calling upon informational sources you have compiled in advance. However, if there appears to be an imminent danger of suicide, the call-handler's responsibility is to immediately refer the caller to agencies trained to handle such emergencies.

ALWAYS MAINTAIN A POSITIVE ATTITUDE; THIS WILL HELP INSTILL A SENSE OF HOPE IN THE CALLER.

Appendix B, Item (a)
FORM FOR COMPILING
INFORMATION NEEDED FOR REFERRALS IN RESPONSE TO CRISIS CALLS

I. TSA Physicians Referral List for the Chapter Area

Other Sources of Support:

1. Therapist who can counsel people with TS:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

2. Psychologist or other Allied Professionals able to provide testing for people with TS.

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

3. Hospital emergency rooms:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

Legal services:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

Educational advocates:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

Appendix B, Item (a)
FORM FOR COMPILING
INFORMATION NEEDED FOR REFERRALS IN RESPONSE TO CRISIS CALLS
(Continued)

Other Sources of Support: (continued)

Vocational rehabilitation service

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

7. Residential alternatives:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

8. Emergency hot lines:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

9. Police precinct:

| (Name) | (Address) | (Phone) |
|--------|-----------|---------|
|--------|-----------|---------|

Notes:

Appendix B, Item (b)

Suicide Hotline, to be supplied by TSA, goes here.

B. PARENTING

This section of this Manual is provided to TSA leaders to help you better understand the issues that affect families where a member has TS, so that you may learn how to effectively help them. Over 70% of people who have registered their diagnosis with TSA are under 18 years of age. It is safe to say that the majority of issues and problems which a TSA chapter leader will be asked to deal with will involve matters relating to parenting.

A formula indicating the right methods of parenting, or the wrong methods is simply unknown. In general, research on parenting of handicapped children covers all handicapping conditions. Psychologists theorize that diagnosis of a chronic disorder in a child often causes parents to suffer through a “grieving” period, much the same as if the child had died. Parents naturally want and hope for a “perfect” child, and a handicapping condition often causes a parent to feel that their child is imperfect. Parents may feel they have “failed” as a mother or father.

A parent who suspects that TS is hereditary in his/her family may feel overwhelming guilt and sorrow. In addition, parenting of a TS child can be complicated by the realization by a parent when their child is diagnosed with TS that they also have the disorder. Thus, this parent must also cope with their own TS along with their child's.

The more familiar a handicap is (i.e., mobility impairments, sight impairments, etc.), the easier it probably is for a parent to get through the grieving process quickly. These are disabilities which are easily understood by the family and the public, eliciting feelings of sympathy and compassion. The more unique and less understood handicaps (i.e. Tourette Syndrome, learning disabilities, behavioral disorders, etc.), sometimes elicit feelings of disdain or fear from strangers. These families may understandably have a more difficult period of adjustment.

The grieving process often includes periods of guilt, rage, resentment, denial, isolation and then, finally, acceptance. To understand these emotions fully, you may wish to read books about grieving which were written by Dr. Kubla-Ross.

Very often, one parent may graduate from one stage of the grieving process to another at a faster pace than their spouse. Problems can occur when one parent's progress becomes arrested at one stage, while the other parent quickly strives toward the end stage of acceptance. Some parents might adjust in only a few days, while others may take months or years.

Typically, a family facing this type of a problem might tell you about situations such as the following:

- I just can't stop crying! As soon as my son leaves for school I cry for a few hours. Then when he comes home, I try to act brave.

- Why did this happen to us? What did we do to deserve this?
- My husband just doesn't understand! He expects my son to do his homework as quickly and as neatly as other children. And he gets angry at him when he doesn't catch a ball as well as other children on the baseball team.
- I just can't stand people staring at us in a restaurant or shopping mall. I refuse to take my child to those places. We stay home a lot.
- My daughter could do anything as well as other children. She's just not motivated. She doesn't even try!

Another reaction, equally detrimental to the child, may occur when a parent seizes on the diagnosis of TS as an excuse for all the problems his/her child has. While acceptance of a handicap is healthy, this "over acceptance" is not. Acceptance, therefore, requires a good understanding of each child's assets and liabilities. While children should not be pushed beyond their capabilities, it is essential that they be encouraged to participate in life's pleasures and duties to the fullest extent possible. It is sometimes necessary to revise one's own expectations of a child according to the nature and degree of the child's handicap.

A few suggestions: Children with TS do better with more structure, more firmness and consistency than children without TS. Let the child know what is expected of him. Give him a schedule so that he knows what to expect each day at what time. Beware that the child does not become the center of all attention and concern within the family. Foster his talents and provide an environment at home which is suited to his need. TS symptoms need to be expressed at home without disapproval of the family. Chapters may want to refer parents to the TSA brochure, "Problem Behaviors and Tourette Syndrome by Bruun, Rickler, and Kelman-Bravo, especially the second part, "Management Hints for Children with TS and Behavior Problems."

As the parents learn about TS, they begin to accept their child as one who is dealing with a neurological condition, and guilt and blame are replaced with compassion and understanding. We must recognize that a parent's acceptance of a child will encourage the child to feel that he/she will be accepted by the people who matter most throughout life. Reality dictates that socially unacceptable TS symptoms may interfere with the child's social relationships even when he grows up. But problems of this nature may matter less if the child has had a stable and secure childhood.

Most importantly, parents should care for themselves. When they are at the end of their rope, they deserve "time out" also. Parents must consider their marital and individual needs as being of primary importance to the family duty. TS parents can become depleted. They need to "refuel" by going out for social occasions, and attending parent support groups can be sustaining.

Some Case Studies

Researchers have found it difficult to relate the degree of a TS child's successful adaptation with the severity of his/her symptoms. Scientists at Yale University have written that the degree of related symptoms such as hyperactivity, learning disabilities, intelligence level, family support, etc. have a greater impact on the TS person's life than do the tics and vocalizations. Some people with very severe TS symptoms have coped very well, and some with mild symptoms have coped very poorly. Why?

There is an obvious benefit to a strong, supportive family which can offset the adverse effects of some of the more problematic symptoms of TS. If a mother cries excessively because of her child's diagnosis, the fact that her eyes are dry when he returns home from school each day will probably not help the child. Children often have a sixth sense, and they can feel a parent's concern and sadness. If a child senses that his TS symptoms are disruptive to a family, he might blame himself for something over which he has no control. This unending cycle of blame and sadness can erode the family structure. In essence, the less attention parents pay to their child's symptoms, the better off a child with TS will be.

Adults who have coped well with TS often credit their parents for their successful coping strategies. "My symptoms were not important to my mother," one adult told us, "so they were not important to me. We visited friends and relatives, went to restaurants and movie theatres, no matter how bad my symptoms were. It never occurred to me that I should be ashamed, and I never will be. Today if my symptoms bother my co-workers or passers-by on the street, I figure it's their problem, not mine."

Another adult with mild TS symptoms is today dependent and isolated. Living with parents at the age of 30, this woman never worked and is afraid to leave her home. She recounts tales of her mother's refusing to allow her to go shopping because her TS symptoms elicited stares from strangers. When she was home, her mother monitored her symptoms, advising her not to see friends when her tics were bad, or to avoid stressful situations. At times she was allowed to stay home from school where she received sympathetic treatment. When she wanted to go to summer camp, her mother wondered aloud what would happen if her TS symptoms worsened while she was away. Many of her parents' fears were transferred to the child, and it quickly became more comfortable to stay home where her family "understood" her disorder.

Probably the greatest frustration of having a child with a handicapping condition is a hopeless feeling that a parent can do nothing about it. Mothers, in particular, are taught by society that it is their duty to keep their children healthy. In this context many parents seem overly concerned about head colds, abrasions and mild fevers. Most parents stock a good supply of over-the-counter remedies for

these minor ailments: antihistamines, aspirin, bandaids, etc. For most, these remedies assist in “curing” a child from intrusive, discomforting conditions, allowing parents to feel they’ve done their job well when a child is “feeling better.”

When a child is diagnosed with a chronic handicapping condition such as TS, a parent often feels powerless and ineffective. It seems that nothing they can do will “cure” the child. This thought can be translated into a feeling of “failure” because he/she is not a “good” parent. More importantly, parents often need to feel that they are in “control,” and a lack of control over their child’s fate can potentially throw the family into turmoil.

Some parents might try to raise medication until no TS symptoms appear, and then will be distressed by the appearance of side effects. Others might express their repeated distaste for physicians who failed to help their child, changing doctors frequently and habitually. Still others might search for home remedies with curative powers in their quest for some “control” over their child’s condition.

All of the above courses of action can serve to keep the TS child’s attention focused on his symptoms, while he should be trying to make the tics minimally important in his life. We must help to guard against making these children “perpetual patients.”

What Can A TSA Chapter Do To Help?

We must recognize that a parent’s need to do something about a child’s chronic disorder can be channeled into creative energies. We can illustrate to these parents that they can do something about their child’s fate by working through TSA’s programs. One parent will not find the cure alone, but many parents working together can muster the energy, talents and finances to find the cure! Instead of a parent wasting negative energy on resentment of medical professionals, he/she can use that energy delivering TSA medical education literature to every doctor in their town. Instead of dragging their child from doctor to doctor they can raise money for research to find improved therapies and eventually, the cure.

No person is too busy to help. Working mothers can address and seal envelopes on the weekends, fathers can sell raffle tickets in their offices. In this manner each will feel they are doing something to ensure a better life for their child, and for other children who will be diagnosed in the future.

Families should be encouraged to “accept” a child with TS and all the inherent imperfections and problems. Therefore, one of the most valuable services you can offer to parents is a feeling that they are helping their own child through participation in the TSA. Eventually they will learn that the greatest resource is themselves, their own inner strengths, their creative abilities, and the ability to share with others.

It is important to remember that TSA leaders must often wait until a parent is ready to change a negative behavior into a positive and constructive attitude. Have patience! He period of adjustment can be hard for parents, but they will eventually understand your message. TSA Parent Support Groups are a very helpful means through which parents can meet others who are “in the same boat” who may have developed helpful coping strategies.

D. TOURETTE SYNDROME RAP SESSIONS

1. WHAT IS A RAP SESSION?

Rap sessions are discussions, that have the elements of pleasant conversations, among people who have had common experiences. Rap sessions can be held in several different contexts within TSA chapter programs:

- Rap Sessions as a Chapter Meeting Program:

Sometimes a chapter will choose to have a general chapter meeting in the form of a rap session, at which the participants bring up and discuss matters related to Tourette Syndrome that are of concern to them. While this form of chapter meeting, planned as a stand-alone event by the Chapter Program Committee, can be interesting to some participants, it does not provide the on-going interaction that characterizes a rap group that can provide peer group support for people with TS who want to explore how to handle the difficulties they may face as a regular part of their lives. Small chapters or newly forming ones are more likely to use the rap session as an occasional chapter program format than are larger, more established chapters.

- Rap Sessions Within the Support Group Format:

Local area support groups provide the program format which lends itself best to planning for rap session activities. Support groups offer a variety of programs—speakers, panels, etc. If the support group chooses, it could make rap sessions a regular program offering.

However, the most satisfactory rap sessions are likely to be those which are planned within the framework of the local support group to meet in regular sessions in a small enough geographical area to allow for convenient, frequently scheduled meetings.

Whichever form these rap sessions take—whether they are conducted as part of a broader support group program or are conducted as the sole program of a rap group—the group must operate as a part of a TSA/chapter and must have signed the Support Group Statement of Understanding. (See TSA Support Group Manual.)

2. DETERMINING THE INTEREST IN RAP SESSIONS

A chapter that would like to explore the interest of its general membership in rap sessions might want to include a questionnaire in its newsletter to find out the general level of membership interest in these sessions.

However, families or individuals interested in attending regular, on-going rap sessions will expect the sessions to be held in a convenient, near-by location so that they do not have to travel too far. Therefore, when some level of interest in a rap session in a specific area has been indicated, the chapter must follow-up to determine the extent of local interest.

A sample questionnaire is given as Item (a) in the Appendix of this Section of the Manual. To determine members' interest in rap sessions, this form should be sent by the chapter to everyone who has participated in local area Support Group activities, as well as everyone else on the chapter mailing list from that area. Some members who have not participated in regular Support Group activities might be interested in rap sessions. The same form could be distributed at Support Group meetings to determine the interest of Support Group participants in rap sessions.

3. LEADERSHIP OF RAP SESSIONS

Good leadership must be a primary concern of the chapter that decides to sponsor rap sessions. Effective rap sessions have been held with lay leaders as well as with professional leaders, but the leaders must be chosen carefully to assure that the groups will be conducted in a manner that will be truly beneficial to the participants.

Lay Leadership

Some informal rap sessions are lay led by a person who has shared the common experiences of the group. Since everyone in the group will have experienced similar problems, a sense of community can be readily established.

Lay leaders may have difficulty keeping a group's discussion on the topic, stopping one person from dominating the conversation, or handling problems which a professional would recognize as beyond what can be dealt with in a social setting and which require individual counseling. If the chapter chooses to have lay leaders, it is, therefore, important that they be well trained and knowledgeable.

It might appear that the best quality of a rap session lay leader would be the ability to listen intently. In actuality, however, these leaders are often

required to recount their personal experiences again and again in order to help others. Concurrently, the leader continues to benefit by learning more about his/her own problems.

A person who has helped others for a long period of time can “burn out.” If it appears to become more and more difficult for a lay leader to recount their own experiences, the support group or chapter should attempt to groom a replacement so that the lay leader who has become exhausted can move on to other organizational duties.

Many people come to rap sessions seeking a “role Model,” a person who can show them that it is possible to live a satisfactory life with Tourette Syndrome. Others may come because they or their child is newly diagnosed and they want to learn as much as possible from others who have had similar experiences.

Professional Leadership

It may be difficult to find a person with TS, or a parent, who is willing and able to act as a lay leader, and in many cases chapters have preferred to arrange for professional counselors. Sometimes professional volunteers can be located within the chapter (for example, a professional who is a sibling, friend, relative or teacher who is familiar with TS). If a volunteer professional cannot be recruited, it will be necessary to hire a professional on an hourly or a per-session basis.

A promising source of help might come from local colleges or universities with social work and/or psychologist training programs. Many social workers and psychologists must spend a certain number of hours in the field before they are eligible for their degree. Arrangements can often be made with these schools to provide training for their students by allowing them to lead your chapter’s rap sessions. In addition, the Social Services Departments of hospitals sometimes will provide the pro bono services of a social worker to conduct chapter or support group rap sessions.

Informal Leadership

There are some situations where formal leadership is not needed or even appropriate.

If a rap group is comprised of only a few members, it may be better to simply meet and share ideas and experiences as an informal group. It can, however, be helpful to ask one person in attendance to act as an informal facilitator to keep members on track and to prevent the domination of the meeting by one individual.

Some rap groups have specialized interests, such as an adult rap session. These may actually be most beneficial if organized as social or sport-oriented events such as bowling. In these cases the rap session is usually simple friendly interaction over pizza or a cup of coffee at the end of the evening. In these situations, there should not be a need for any leadership role.

4. WHAT RAP SESSIONS CAN ACCOMPLISH

For the person with TS the main thrust of these sessions is likely to be development and/or maintenance of a positive self-image. Many people with TS are bullied, harassed or made to feel inferior. When they come to the initial session they often feel bad about themselves. It is helpful for them to learn that they are not alone and that others with TS face similar experiences. Those who are coping poorly will benefit substantially from listening to those who cope well. Everybody will feel better just by being able to talk about their feelings to others who will truly understand.

Parents, on the other hand, usually participate for a variety of other reasons. They often feel that many aspects of their lives are no longer under control, and participation in rap sessions can help them regain some sense of that control. When parents verbalize feelings such as: "I hate it when he barks or spits while in the store," the group can help these parents deal with these real feelings. It is always painful and sad for a parent to see a child in this condition and, yes, it is also embarrassing. An effective rap group can do more to help such a parent than to soothe the parent by inappropriately saying, "You shouldn't worry about that."

Rap sessions can be particularly helpful to the families of newly diagnosed individuals with TS. It is often a great help just to learn that they are not the only ones dealing with TS, and sensitive individuals who are more experienced with dealing with TS can share the coping skills they have learned.

TS symptoms cannot be eliminated, but parents' fears and anxieties can be alleviated by helping them to place less importance on symptoms and more importance on the child. A parent's discomfort with the child's TS symptoms is easily sensed by a child. The parent can be made aware that often some of the problems their child faces as a result of TS bother the parents more than they do the child. Home must be a safe haven for all children, but especially for a child with TS.

5. DISCUSSION SUGGESTIONS

- "Who owns the problem?" a rap session leader may ask. When a mother feels discomfort and shame because she notices people staring at her child in a store, is it the child's problem or the parent's problem, or is it the stranger's

problem? How can the problem be alleviated? One parent might decide to increase medication that night. Another might approach the stranger, offer a TS Q&A brochure and say, "Please don't stare at my son. He has Tourette Syndrome." Another parent might simply feel sorry for the rude, ignorant stranger and forget about the incident, while still another parent might decide not to allow the child with TS to go shopping in the future.

The rap session leader could discuss each of these reactions so that understand the pros and cons of each attitude and the motivation behind each parent's response to this common situation. If the goal is to prevent persons with TS from becoming reclusive, parents must show them, while they are children, that they need not be ashamed of their symptoms.

- Medication is often a main topic of discussion for parent groups. Leaders should take care that parents not dwell on this topic too much. Many parents tend to feel that medication is the sole answer to their problems, ignoring other solutions such as coping skills. In truth, the main goal of rap sessions for parents is to maximize coping strategies. Parents can be asked to consider whether they administer medication or raise it because the TS symptoms bother the child or because they bother the parent? Many physicians indicate that medication should be administered only when symptoms bother the person who has TS.
- The rate of adjustment to the diagnosis of TS by each of the parents is a common family problem rap sessions can address. When a child is diagnosed with any chronic disorder, parents often go through a grieving process similar to that experienced when a loved one dies. Psychologists have theorized that these parents are mourning the loss of a "perfect" child, and must adjust to accepting a child who is no longer perfect. Spouses sometimes make this adjustment at different rates. For example, a father may have a more difficult time than the mother when their son has been diagnosed and might show unreasonable impatience when his son can't play ball as well as other boys (eye-hand coordination problems). Or he may seem to lack compassion and understanding of symptoms by declaring, "TS or no TS, what that kid needs is some firm discipline!"

Through talking and sharing at rap sessions, these parents can learn that others have had the same feelings and acted in the same way. And they can learn that avoiding emotional damage to a child with TS depends on a warm, loving home where the child is accepted with all his flaws as well as his strengths.

It might be beneficial to appoint a father who has good coping skills as a liaison to other fathers who are having adjustment problems. If such a father in your chapter is willing to spend time on the phone with other parents, he may be able to help families through some difficult times, and perhaps

encourage reluctant fathers to participate in rap sessions. And sometimes two fathers can relate to each other better than to a professional who may in some way make them feel threatened.

An astute rap session leader will recognize which parents may need individual counseling, and will refer them to therapy beyond the scope of the rap sessions.

The issue of guilt can be addressed during rap sessions. Parents often feel guilty about punishing a child for uncontrollable symptoms before he/she was diagnosed. Others may feel guilty because they or relatives have tics or TS and they may take blame for having passed TS on to their child. These feelings are natural, and can be dealt with in rap sessions.

The most damaging aspect of guilt involves the parents' attempt to "pay for their sins." They sometimes spoil a child and/or over-protect him simply because they are trying to alleviate their own guilt. This must be avoided if they expect the child to mature into an independent and productive adult. Parents also have to recognize how their own feelings of guilt affect their behavior. A child with TS should be raised the same as the child who does not have TS---expected to do household chores, attend social gatherings, etc. If the child is allowed to use TS as an excuse for avoiding some activities or responsibilities, his future could be threatened.

6. CONCLUSION

People with TS or their families are rarely able to talk about how TS affects their whole lives. Rap session can serve as a podium, a place where one can discuss events and feelings that would not be understood outside the TSA group.

There are two imperatives for participation in rap sessions:

- One is that the participants treat each other in a non-judgmental way;
- The other is that everyone who participates in the rap session understands that the rap session discussions are confidential and scrupulously respects this obligation for confidentiality. This means that the identity of other participants is not divulged. It also means that the comments of participants are not repeated outside of the rap session, even in a context in which the speaker is not identified.

In organizing rap sessions, potential participants should be asked to make a commitment that they will attend every session until the series of rap sessions is scheduled to end. A series of rap sessions should last 6 to 10 weeks. When the end of the scheduled sessions approaches, ask the group if they would like to continue to meet or if they would prefer that the group dissolve. Sooner or later, that group will choose to dissolve, and after a few months you can start again with a new group of individuals who will need the support of a rap session.

II. THE NATIONAL TOURETTE SYNDROME ASSOCIATION RESEARCH PROGRAM

The Tourette Syndrome Association maintains a national program of medical, clinical and basic scientific research. This program is conducted under the direction of the Association's Scientific Advisory Board (SAB), a volunteer body of leading scientists in Tourette Syndrome research, and is the only research program conducted by the Association or its chapters.

The reasons for maintaining a single, unified program of TS research, directed by the Association's SAB are three-fold:

TO ASSURE THAT ALL TSA FUNDS, WHETHER ORIGINATING IN THE ASSOCIATION OR ITS CHAPTERS, ARE SPENT ON THE BEST AND SCIENTIFICALLY MOST PROMISING RESEARCH. This can be assured only if all research proposals, in competition with one another, are judged impartially by qualified evaluators.

TO ASSURE THAT MONEY AVAILABLE FOR TS RESEARCH IS NOT WASTED ON REDUNDANT RESEARCH OR RESEARCH OF LESSER MERIT. The SAB's peer-review process is available to all medical, clinical, and basic scientific TS research projects, and is the Association's and the chapters' guarantee that all available research money is prudently spent, thereby promoting the greatest benefit to people with TS. The SAB, because of its eminence in the field of TS research and its global knowledge of the state of the art in the field of TS research, is best qualified to make judgements on the merits of research proposals.

- TO CONTINUE TO ATTRACT THE ASSISTANCE OF EMINENT SCIENTISTS WHO VOLUNTEER THEIR EXPERTISE IN TS RESEARCH BY SERVING ON THE SAB. SAB assistance assures that the Association's Research Program is of the highest quality and of great stature in the scientific community.

A. CHAPTER SUPPORT OF THE TSA RESEARCH PROGRAM

Chapters provide support for the medical, clinical and basic scientific research program of the Tourette Syndrome Association by financial contributions to the Association's Permanent Research Fund. If chapters were to accept, or contribute, money for research in which the investigator, the project, or the site of the research facility is designated by the donor of funds, or by the chapter, without the project's being submitted to the SAB for peer-review and without SAB approval for funding, there could be no guarantee that such research is of the highest merit. The Association's Research Program would lose credibility in the scientific community, and the Association would no longer be able to attract leading scientists to its SAB if its peer-review process were by-passed by the Association or any of its chapters in the awarding of research funds.

Chapter Assistance in Non-TSA Sponsored Research

From time to time chapters are asked to assist in local research projects not funded by TSA by recruiting subjects for such research from among the chapter members. These can be an altogether worthy undertakings. However, to assure that chapter members are asked to participate only in projects of scientific merit, it is TSA policy that, before agreeing to cooperate in such research, chapters direct the researcher's request to the TSA Director of Medical and Scientific Programs. The TSA Medical Advisory Board will then review the research project to assure that it is of scientific merit before the chapter contacts its members concerning participating in the project.

B THE TSA BRAIN BANK PROGRAM

A brain researcher, as do all types of scientists, needs tools with which to work.

To the best of our knowledge, TS is a disorder found only in humans and as yet there is no animal model that can be used in the search for the cause of TS. Therefore, it is in the human brain tissue that the secret of TS is hidden, and it is only in the scientific study of human brain tissue that the elusive answer will be found.

The scientific community is eager, and even desperate, to obtain additional TS brain tissue specimens for study. It is up to all of us, the TSA family, to cooperate with them in this crucial endeavor. However, we must be sensitive to the fact that mere discussion about human brain tissue donation can be discomfoting to some people. They will not be eager to listen to presentations about this subject at chapter meetings; nevertheless, this topic must be brought up from time to time if we are ever to achieve major medical breakthroughs.

1 How to Present the Brain Tissue Program

Through your chapter newsletter articles and presentations at chapter meetings, you can explain to TSA chapter members that major advances in the management of other neurological disorders occurred only because scientists were able to analyze post-mortem brain tissue. For example, researchers learned through examination of Parkinson's disease brain tissue that the brains had stopped manufacturing dopamine. Subsequently, they were able to determine that L-Dopa was effective therapy for Parkinson's.

You might preface your remarks with a compassionate recognition of how difficult this topic is to speak about, and that you are aware that it may cause discomfort for some. On the other hand, you can explain why you **MUST** bring up this subject as it a necessary step in our mutual search for a cure.

2. Who can Donate Brain Tissue?

- A. Persons with TS.
- B. All family members related to a person with TS.
- C. Non-related people whose tissue is needed for controlled studies. This means that researchers need samples of non-affected brain tissue which they can compare with TS brain tissue. Without these controls, it will not be easy to identify a structural or chemical abnormality.

3. How to Give Permission

Ask chapter members to register with the TSA Brain Bank Program. Remind them to carry the donor card in their wallet at all times. They also need to inform next-of-kin of their intentions.

4. Death of a Donor

To be useful, brain tissue must be removed and preserved within a very few hours of a person's death. In the event of death, please collect immediately to:
1-800-272-4622, 1-800-BRAIN BANK, or (617) 855-2400

It is important to note that some deaths (accidental) occur without warning, but others may occur after a lengthy battle with disease and can be predicted. In these cases, it is advisable to speak with the family about the brain donor program BEFORE the death occurs.

5. Can Someone Other than the Donor Decide to Make the Gift?

Yes. If the donor either cannot sign the card or has never indicated that such a gift should not be made, the following people in order of priority may decide to make the gift.

The spouse

And adult son or daughter

Either parent

An adult brother or sister

A guardian of the person at the time of his/her death.

6. How Will Brain Tissue Be Used?

TSA is sponsoring a consortium of brain research experts who will be using these specimens. There are many different research projects now in progress which need tissue. Most scientists will compare diseased brains with normal brains to see if they differ biochemically, histologically, structurally, etc., to try to determine the cause and cure of TS.

7. Is there an Age Requirement for Donors?

Anyone 18 years of age or over, and of sound mind, may become a donor by signing a card. An individual under 18 years of age may register if either parent or a legal guardian gives consent.

8. Who Underwrites the Cost of Brain Removal?

TSA will pay the pathologist's fee and the cost of transporting the deceased.

9. Will Organ Donation Affect Funeral and Burial Arrangements?

It is almost impossible to discern that the brain has been removed. Customary funeral or burial ceremonies can proceed as soon as the brain is removed.