Tourette Syndrome Association
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A Letter from Peter Hollenbeck, Ph.D.

Dear Friends,

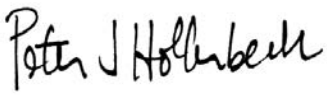
Like many of you, I struggle each day with the symptoms of Tourette Syndrome. My tics and compulsions have presented hurdles in my education, work and social life. Throw in the difficulty in getting a good diagnosis, and the lack of robust treatments, and TS can seem pretty daunting.

However, in addition to being a TS patient, I am also a neuroscientist. And I see great cause for hope! At this time, research on TS is advancing on many fronts: genetics, brain imaging, behavioral science, neuroscience and neuropathology. I foresee a time, not so far off, when this research - much of it initiated by grants from the TSA—will produce the tools for vastly better diagnosis and treatment, and perhaps ultimately a cure.

In the meantime, all of us with TS have to keep plugging, to let our lives and accomplishments stand as testimony to what can be achieved right now with—or despite—our TS. But I also hope that I can leave something important and enduring to the future. That is why I decided to become a donor to the TSA Brain Bank Program. Today I am asking you to consider doing the same. By giving the gift of our brains after we have passed on, we can make possible the most advanced and detailed studies of brain structure and its role in the development of TS. Already, studies with TS Brain Bank material by neuropathologists at Yale are beginning to answer the most fundamental questions about how the TS brain differs at the cellular level. These exciting studies are likely to lead to a much deeper understanding of how TS arises, and to better-targeted treatments. They would be impossible without the precious gift of tissue from generous donors who have passed away.

Like all organ donation, brain donation is a deeply personal decision. It has the potential to advance research and improve the lives of children and adults with TS everywhere. I hope that you will give this request your consideration.

All the best,



Peter J. Hollenbeck, Ph.D.
Professor of Biological Sciences, Purdue University
Co-Chairman, TSA Scientific Advisory Board

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Why Study the Brain?

The Harvard Brain Tissue Resource Center (HBRC) [www.brainbank.mclean.org] is located at McLean Hospital, Belmont, MA and is a centralized resource for the collection and distribution of human brain specimens for research. The center is dedicated to providing brain tissue for the study of a variety of brain-based behavioral disorders. To enhance our understanding of TS, for the past decade, the Tourette Syndrome Association, Inc. has partnered with the HBRC to provide brain tissue to Neuroscientists dedicated to studying the basic cause of TS.

Research over the past decade has shown that the study of human brain tissue is essential to increasing our understanding of how the nervous system functions. Unlike imaging studies such as PET and MRI, state-of-the-art molecular and microscopic studies of brain tissue give an understanding of the underlying mechanisms responsible for neurological disorders. As genes implicated in TS are identified, postmortem human brain research will play a significant role in the development of a genetic test and even improved treatment strategies.

Unlike some neurological disorders that disrupt the function of a single cell type in the brain, TS is believed to involve a whole brain circuit. A number of studies over the years have suggested that TS comes about because of a malfunction in the basal ganglia, a region of the brain that is thought to facilitate desired actions while inhibiting undesired or inappropriate ones. Indeed, in one anatomical study using brain tissue obtained from the TSA Brain Bank, people with TS were shown to have more neurons in the basal ganglia and that the types of neurons in this location are different when compared to unaffected individuals.[1] In another study, also using tissue from the TSA Brain Bank, a variety of differences in gene expression were identified in the basal ganglia.[2] Neuropathological differences in the brains of people with TS may, however, extend beyond the basal ganglia.[3]

Findings such as those described above, will ultimately lead to a better understanding of TS and may eventually lead to a cure. These and other important discoveries are made possible by patients and families who donate brains for research. Please consider registering with the TSA Brain Bank program. Since brains from unaffected people are needed for comparative purposes, you do not need to have TS to register as a donor.

To register, please call 1-800-BRAIN-BANK, (1-800-272-4622).

Some Recent Scientific Publications

1. **Kalanithi PSA, Zheng W, Kataoka Y, DiFiglia M, Grantz H, Saper CB, Schwartz ML,Leckman JF, Vaccarino FM.** Altered parvalbumin-positive neuron distribution in basal ganglia of individuals with Tourette syndrome. *Proceedings of the National Academy of Sciences, 102: 13307-13312, 2005*
2. **Hong JJ, Loiselle CR, Comi AM, Becker KG, Singer HS.** Microarray analysis of postmortem putamen from Tourette syndrome patients. *Journal of Neurological Sciences, 225: 57-64, 2004*
3. **Minzer K, Lee O, Hong JJ, Singer HS.** Increased prefrontal D2 protein in Tourette syndrome: a postmortem analysis of frontal cortex and striatum. *Journal of Neurological Sciences, 219:55-61, 2004*

To obtain copies of these articles, try your local medical library or search online at *PubMed*, a service of the National Library of Medicine, which provides access to over 11 million medical and scientific articles. *PubMed* includes links to many sites providing full text articles and other related resources.

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Religious Perspectives on Brain Donation

Persons seeking religious guidance may find it helpful to discuss their spiritual concerns with a religious leader of their choice. The following is a brief summary of the positions of several major religions on the subject of organ and tissue donation.

Buddhism
Buddhists believe that the decision to donate organs or tissues is a matter of individual conscience. There is no written policy on the issue.

Catholicism
The Catholic Church supports organ and tissue donation provided that free and informed consent of the donor or the donor's family is given.

Christian Science
The Church of Christ Science holds no specific position regarding organ donation.

Hinduism
Hindus are not prohibited by religious law from donating their organs.

Islamic Society
Although the Moslem Religious Council initially rejected organ donation, it has since reversed its position provided that written consent is obtained from the donor.

Jehovah's Witness
Organ or tissue donation is not encouraged.

Judaism
Donation of tissues or organs for medical education and research is acceptable, provided that individuals specify in writing that their bodies can be used for the purposes of scientific research.

Protestantism
Most protestant denominations endorse and encourage organ and tissue donation.

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Why a Brain Bank?

The key to treating and ultimately curing TS lies in scientists being able to fully understand the brain's basic biochemistry. What many of us don't realize is that this knowledge can only be achieved by studying *actual* brain tissue. The critical question is—how do you go about getting brain tissue to study? Unlike other organs of the body, every cell of a living person's brain is critical to its function and thus cannot be utilized for research purposes.

So the most critical resource in our effort to uncover the disorder's secrets, can only be obtained from deceased individuals with TS. Given the fact that mere *discussion* of tissue donation is such a sensitive subject that many would rather not even talk about it (let alone register as donors), it is no wonder that brain tissue is in such short supply.

Peter J. Hollenbeck, Ph.D., Professor/Associate Head of Biological Sciences at Purdue University and Co-Chair of TSA's Scientific Advisory Board (SAB), is a scientist who has TS and understands just how many people feel about the issue. "Most people have a vague idea about 'donating their bodies to science,' but few really understand what a great deal of good it can do," he explains. "Neuroscientists use brain tissue to study the structural and chemical basis of disorders such as TS. I plan to donate my brain to the bank—but not until I've gotten my kids through college! Of course, with any luck we'll have cured TS by then."

With all the advances in neuroimaging technology, it's tempting to think that actual tissue isn't needed, but according to SAB Co-Chair Jonathan W. Mink, M.D., Ph.D., Associate Professor of Neurology, Neurobiology, Anatomy, and Pediatrics at the University of Rochester Medical Center, this simply isn't so. "Despite substantial advances in imaging the brain, there are still limitations to neuroimaging," he states. "Studying the brains of people with TS has the potential to reveal neurobiological mechanisms that will lead to better understanding of TS and better treatments."

Flora Vaccarino, M.D., a Yale University Child Study Center researcher, uses tissue from the TSA/Harvard Brain Bank Program in her work. Dr. Vaccarino has a very clear idea about the difference between tissue research and the interpretation of brain images. "The resolution of neuroimaging studies is about 1,000 degrees lower than brain histological studies. For example, neuroimagers cannot tell how many or what type of neurons a region has. Post-mortem brain studies can tell us the type and number of neurons that may be altered or different from normal in a specific brain region. It is very important to discover whether we find any abnormalities in the tissue retrieved from those with TS."

Brian Ciliax, Ph.D. of Emory University is Project Coordinator of the TSA Brain Tissue Research Program. He maintains a database of available tissue and oversees its distribution. Along with a committee of SAB members, he reviews all investigator requests for tissue samples from the bank.

Because there are no animal models available, Dr. Ciliax emphasizes the special importance of human brain tissue study in TS-related research. Once genes are identified the ". . . brain tissue will be even more important to look at for changes in expression levels and patterns of those genes." He also stresses the importance of comparing affected and non-affected brain tissue, adding, "All brain disorder research depends on comparing normal with TS affected specimens in order to find out how they differ. Surprisingly, such normal cases are difficult to obtain. This is because the average person is not aware of the acute need for such donations. Thus, even friends, relatives and others concerned with the advancement of research can make a significant contribution to research by registering their intent to donate their brains. This is true whether it's for TS research or for studying other brain based disorders."

Scientifically, the need for more of us to become brain tissue donors is clear. Non-scientist member of the TSA family, Education Specialist Sue Conners, brings to the subject a down-to-earth perspective with her typically upbeat attitude and sense of humor. "I thought about my descendants and the many people with TS who will come after me and I realized that my brain was probably going to be more useful to humanity after I was gone than while I was alive! So I made the decision to register my intention to donate it to the brain bank. I have always tried to have a good sense of humor about my TS, and it's helped me survive 50+ years with the disorder. I figure that once I am gone, I will have no further use for my brain, so why not let it be of use to someone else? Maybe my sense of humor will come with it and help someone else survive TS like I have."

— Reprinted from the TSA Newsletter, Spring 2006

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Registration Step-by-Step

1. Fill out the online registration form at http://tsa-usa.org/forms/brain_bank.htm or call the Harvard Brain Bank to register at 1-800- BRAIN BANK (1-800-272-4622).
2. Upon receipt of your registration, the Harvard Brain Bank will send you an acknowledgement letter together with permanent donor registration cards.
3. Keep one of the cards in your wallet and give the others to your next of kin.
4. Inform your doctor and family members of your decision.
5. If you are living in a nursing home, notify the home's administrator of your decision and give them one of the donor registration cards.
6. If you are ever hospitalized, be sure that the donor registration card is on your hospital chart and tell your medical care team of your decision.
7. Time is of the essence when harvesting brain tissue. Designate someone to call the Harvard Brain Tissue Resource Center (1-800-BRAIN-BANK, 1-800-272-4622) as soon as possible after your death. The Brain Bank operates 24 hours a day, 7 days a week.
8. Even if you are a registered donor, still your next of kin will have to give permission for the tissue to be removed and for authorization for the brain bank to acquire your medical records. The required consent forms will be provided to your next of kin prior to the brain tissue removal.
   - Legally, your next of kin is defined as the first to fulfill one of the following requirements:
     - Spouse (unless divorced or legally separated)
     - Adult son or daughter (18 years or older)
     - Parent
     - Brother or sister
     - Other relative (niece, nephew, grandchild, etc.)
     - Guardian
     - Durable power of attorney
9. Once your next of kin has given permission for the brain tissue to be removed, authorized staff from the Brain Bank will arrange for the donation to be carried out by a pathologist in your area. The recovery of the tissue will be performed at the nearest hospital equipped for the procedure. All costs for this procedure will be assumed by the Tourette Syndrome Association; there will be no financial burden on your family for this tissue donation.

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Some Facts about Brain Tissue Donation

A critical shortage of brain tissue is frustrating scientists in their research, slowing progress in probing what causes Tourette Syndrome. Registering your intent to donate brain tissue will ultimately help to provide many investigators with samples they urgently need to pursue promising studies.

Registering as a donor does not, in any way, affect the medical treatment that you receive.

Brain donation does not preclude you from donating other useful tissues such as bone, corneas and skin, but it may not be possible to donate certain other organs.

Because the majority of brain pathology studies are carried out on a very small piece of tissue, each donated brain provides a large and very valuable amount of material that can be distributed among many different researchers.

The decision to become a brain donor is a private one, but to ensure that your wishes are fulfilled you need to tell your family about your decision.

Tissue donation is an acceptable decision by most major religions.

Methods for retrieving brain tissue are not visible and therefore will not affect any type of funeral arrangements. The procedure is conducted confidentially and with dignity.

The Tourette Syndrome Association will incur the cost of brain tissue removal and necessary transportation expenses. Your family will incur only the usual funeral and burial expenses.

You can withdraw your name from the TSA Brain Bank Registry at any time.

Anyone, 18 years or older, is invited to register as a donor. An individual under 18 years of age may become a donor if a parent or a legal guardian gives consent. You do not have to have TS in order to be a donor. All donor information remains anonymous.

For more information or to register call the
Harvard Brain Tissue Resource Center 1-800-272-4622

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thank you

We hope these pages answer all your questions.

Remember that you are under no obligation.
Even after registration, you can change your mind at
any time and withdraw from the program.

For additional concerns, questions or comments,
please don't hesitate to call us at 718-224-2999 and
ask for Heather, TSA Brain Bank Program Coordinator
or email her at tsa_brain@tsa-usa.org