

*FREQUENTLY ASKED QUESTIONS ABOUT...***Tissue Donation**

Donating tissue for medical research is an important and deeply personal decision. Proper planning can help ensure that wishes are accounted for and honored at the time of your or a loved one's passing.

The following is a brief description of the process of donating tissue for medical research through the National Ataxia Foundation under the care and guidance of Dr. Arnulf Koeppen. For more details or to make arrangements for tissue donation please follow-up with Dr. Koeppen directly at his contact information listed below.

Q. Why is tissue donation important?

The examination of diseased tissues by a trained pathologist remains the gold standard for diagnosis. An explanation of ataxia arises from such an examination, and key questions about the severity of ataxia can be answered. Tissues of persons with ataxia are needed to study the fine details of how the brain and spinal cord are injured by the disease. In Friedreich's ataxia, donation may include tissues from the heart and pancreas as well as the brain and spinal cord.

Q. I have decided to donate my tissue, what should I do next?

First, let your next-of-kin know that you intend to donate tissues, including brain, spinal cord, and in Friedreich's ataxia also heart and pancreas. Tissues are

harvested by autopsy, and your next-of-kin will have to sign a formal permission document. Living patients who inquire about tissue donation receive a consent form to enroll as participants with emphasis on their disease. Their next-of-kin, however, become the ultimate donors and secondary research participants. They must complete a new set of documents.

Q. What kind of consent must be given for a donation?

One is formal permission to be enrolled in this research program; the second authorizes release of your private and protected health information to Dr. Koeppen. The "permission" document requires the signature of a witness. To be legally binding, Dr. Koeppen will discuss the consent forms with you over the phone. If you have trouble speaking, you may request that a relative speak with him about the forms and the investigation.

Q. Will my family have access to the results from my tissue donation?

Yes. Feedback to families and the involved physician (at the family's request) is part of the process. A report and cover letter which often contains diagnostic information is mailed to them. Tissues are not intended for transplantation but some families offer donation of corneas and other tissues that are not affected by ataxia or co-existing illnesses.

Q. What are the final steps for tissue donation?

Tissues will be collected according to a specific protocol that Dr. Koeppen forwards to the collaborating pathologist. Your next-of-kin will sign a consent form that allows Dr. Koeppen to use the collected tissue for research.

Q. Are there costs involved?

It is important to note that in some cases additional funeral expenses may apply. Some pathologists and medical centers may request payment for the autopsy. The sum may be as high as \$1,500.

Q. What if I change my mind?

Participation is entirely voluntary. Family members may direct the investigator at any time to end further research, even if the autopsy has been completed and tissues were already harvested for research. Upon request, tissues will be destroyed.

For more information, please contact:

Dr. Arnulf Koeppen
 Professor of Neurology & Pathology
 VA Medical Center
 113 Holland Ave., Albany, NY 12208
 Phone: (518) 626-6377
 Pager: (518) 422-3491
 Fax: (518) 626-6369
 E-mail: Arnulf.Koeppen@va.gov

Provided by the National Ataxia Foundation
 2600 Fernbrook Lane No. Suite 119
 Minneapolis, MN 55447-4752
 Phone: 763-553-0020
 Email: naf@ataxia.org
 Website: www.ataxia.org
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National Ataxia Foundation

2600 Fernbrook Lane, Suite 119 • Minneapolis, MN 55447-4752

Phone: (763) 553-0020 • Fax: (763) 553-0167

Email: naf@ataxia.org • Website: www.ataxia.org