



## Tissue Bank for VHL Research

Human tissue donation is a very special gift that helps scientists identify ways of improving diagnosis and treatment of VHL. Please consider this gift and helping work towards a brighter future with the VHL patients.

There is no financial cost to the family for donation to research. If you donate blood, you may incur a modest charge from your local doctor or hospital to have the blood drawn. In the case of death, the family is responsible for regular funeral/mortuary or cremation expenses.

### Collaborative Program

The tissue bank program is contractual collaboration between VHL Alliance and the National Disease Research Interchange (NDRI, [www.ndriresource.org](http://www.ndriresource.org)).

### Why Donate Tissue

Once considered only “an obscure medical curiosity”, VHL has become one of the most important diseases in the study of cancer. Since the discovery that the VHL gene is mutated within the cells in many forms of cancer including clear cell renal cell carcinoma, breast, colon, etc. there is increasing interest in studying tissue from patients with VHL.

Scientists depend on research donors supplying different types of human tissues and organs for their studies, such as...

- Blood and urine samples (with accompanying medical history)
- Discarded surgical specimens
- Tissues and organs donated after death

### How is the Tissue Used

The tissue is stored in the tissue bank. Researchers apply for tissue to be used for specific projects. Only researchers with approved applications can obtain tissue. **Patient and family identity is confidential and is not disclosed to the researcher.**

### How to Donate Tissue

There are 3 different types of donation, each with a different consent form; donation of a blood, urine or saliva sample, donation of tissue during surgery and donation of tissue on death. NDRI will overnight the forms to you.

**Follow the steps below to pre-register to become a donor.**

1. Request a sign-up kit contacting NDRI at **800.222.6374** or email [bank@vhl.org](mailto:bank@vhl.org).
2. The kit will include materials to indicate the desire to donate surgically removed tissue for research. You or your next of kin and a witness must sign two copies of the enclosed consent forms. You or your family member should retain one copy, and the other should be mailed to NDRI. You will also need to fill out and mail to NDRI the medical questionnaire. All information will be kept in the strictest confidence, and identifying information will be removed before this information is shared with any researchers.
3. Return the completed sign-up kit to:

National Disease Research Interchange  
1628 JFK Blvd.  
8 Penn Center, Suite 800  
Philadelphia, PA 19103  
Fax #: 215.557.7154

Make sure your loved ones, doctors, care givers and attorney are aware of your registration with NDRI. Designate one person as a contact for NDRI.

When a surgery is scheduled contact NDRI. They will handle further details of the specific tissue donation.

In the event of death, or if death is imminent NDRI should be contacted as soon as possible on NDRI will work with your family members, funeral director, hospital or nursing home staff to arrange for the transfer of the body, if applicable, and for the tissue recovery at an appropriate location. Recovery of tissues and organs may be performed at your local hospital, funeral home, or other designated establishment. The removal of tissue is very respectful; and the body can be made available for a timely funeral after donation. A traditional, open-casket funeral service can still take place. The physical appearance of the donor is unchanged.

Even if the is not already pre-registered, but an emergency situation arises and you wish to donate either as a result of surgery or death, arrangements can be made by contacting NDRI.

**Outside of  
the U.S.**

Canadians can contribute to the US bank. Europeans are constrained to donate within country. Contact the primary research project in your country. There are strict laws about sending blood and tissue across country borders. In most cases tissue will be stored within your own country, to facilitate the research projects there.