


[Education](#)
[Research](#)
[Patient Care](#)
[Community](#)
[Departments &
Institutes](#)
[Administration](#)
[Stanford Medicine » School of Medicine » News » Inside Stanford Medicine](#)

NOV. 2, 2009

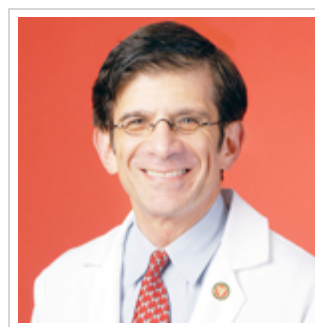
[SHARE THIS VIA...](#)

Stanford helps establish tissue bank, patient registry for lymphatic diseases

BY JENNIFER WELSH

Millions of people in the United States may suffer from lymphatic diseases, but little is known about what causes these illnesses or how widespread they may be. To try to answer these and other questions, researchers at the Stanford University School of Medicine have partnered with the [Lymphatic Research Foundation](#) and the [Feinstein Institute for Medical Research](#) in Manhasset, NY, to establish the first patient registry and tissue bank for patients with lymphatic disorders.

[Stanley Rockson](#), MD, the Allan and Tina Neill Professor of Lymphatic Research and Medicine at Stanford, will oversee the patient registry and tissue bank, made possible by a \$1 million grant to the Lymphatic Research Foundation from a private donor who wishes to remain anonymous. Rockson is also chair of the foundation's scientific and medical advisory board as well as director of the [Center for Lymphatic and Venous Disorders](#) at Stanford.



Stanley Rockson

Most doctors know little of how to diagnose and treat lymphatic diseases, Rockson said, because these diseases are mistakenly believed to be rare. While Rockson estimated that there may be more than 10 million people nationwide with these diseases, he said there's a desperate need for a more reliable estimate. "There is so little substance to these numbers, they are almost fictitious," said Rockson, who added that the registry could "provide valid research to improve the situation of current and future patients."

The vast majority of lymphatic-disease patients suffer from lymphedema, a lifelong problem of disrupted lymph circulation characterized by fatigue, limb swelling and loss of the integrity of the skin. The condition's severity can range from mild discomfort to disabling disfigurement, pain and loss of function.

Lymph is a protein-rich fluid made mostly from blood plasma. When blood plasma exits the circulatory system through the walls of blood vessels, it bathes the cells of the body's tissues. The plasma picks up proteins, cells and debris, all of which is collectively known as lymph. When lymph leaves the body's tissues, it exits through the lymphatic system instead of merging back into the circulatory system. The lymphatic system also fulfills a function called immune trafficking: On its way out of the tissues, lymph passes through nodes, where white blood cells can be activated to attack any invading viruses or bacteria the lymph might have detected along its journey.

When lymph circulation is delayed or interrupted, swelling and inflammation can result

RELATED NEWS

- » [Cancer survivors needed for study of lymph disorder to ease pain, swelling](#)
- » [New animal model offers opportunity to develop therapies for lymphedema](#)

from a traffic jam of lymph that builds up in the limbs. There are multiple sources of blockages but often they are caused by tumor removal surgery, radiation treatment or lymph node biopsy. The only available treatments are physical therapies including skin massage, drainage and pressure bandages, though the long-term effectiveness of these therapies has not been carefully studied.

The lymphatic disease patient registry and tissue bank could help fill this void of knowledge and point to new types of treatment for lymphedema and all of the other lymphatic diseases. The patient registry is being coordinated at Stanford and began officially accepting enrollees on Oct. 18. Tissue samples, to be collected after enrollment, will be stored at the Feinstein Institute.

The Web-based registry will allow lymphatic disease patients nationwide to enroll and provide background data about themselves and their conditions. The information collected will be demographic, symptomatic, psychosocial and socioeconomic, and will include health insurance status, diagnostic criteria, imaging criteria, treatment and outcome data.

Anyone suffering from a lymphatic disease is encouraged to enroll in the patient registry, where personal and medical information will be made anonymous and securely encrypted. The information will be confirmed with the enrollees' medical records and their doctors.

After patients are enrolled, their doctors will be encouraged to send samples collected during treatment, including blood serum and biopsy specimens, to the tissue bank, where they will be stored until requested for biomedical research. The patient data in the registry will be linked to the samples in the tissue bank. The patients will be asked to continue to update their data as their condition progresses.

Analysis of patient registry information and tissue samples will help researchers understand which groups are most affected by lymphatic diseases, how the diseases impact patients, how insurance status affects treatment of these patients and the effectiveness of various treatments. "We want to encourage research into lymphatic diseases as much as possible, not only at Stanford but around the world," said Rockson.

For more information on lymphatic diseases visit www.lymphaticresearch.org. To learn about or enroll in the patient registry and tissue bank, visit the Lymphatic Research Foundation's Web site and click on the "Patients" heading, then the "Patient Registry" link on the left-hand side.

Jennifer Welsh is a science-writing intern in the Office of Communication & Public Affairs.

PRINT MEDIA CONTACT
Tracie White | Tel (650) 723-7628
traciew@stanford.edu

BROADCAST MEDIA CONTACT
M.A. Malone | Tel (650) 723-6912
mamalone@stanford.edu

Stanford University Medical Center integrates research, medical education and patient care at its three institutions - [Stanford University School of Medicine](#), [Stanford Hospital & Clinics](#) and [Lucile Packard Children's Hospital](#). For more information, please visit the Office of Communication & Public Affairs site at <http://mednews.stanford.edu/>.