

8700 Beverly Blvd., Room 2429A ■ Los Angeles, CA 90048-1865
Office (310) 423-4767 ■ Fax (310) 423-0435

Media Contact: Sandra Van
E-mail: sandy@vancommunications.com
Telephone: 1-800-880-2397

HIGHLIGHTS:

More than 10,000 participants are expected to enroll in Cedars-Sinai Medical Center's Women's Health Research Registry™ in the next five years. The registry has been established in an effort to close the gap in the under-representation of women in clinical research. As part of its commitment to helping women improve their health today and in the future, Cedars-Sinai is building this health information database, which it hopes will become a vital component in the search for new and better ways to diagnose and treat women.

WOMEN'S HEALTH RESEARCH REGISTRY AIMS TO IMPROVE WOMEN'S HEALTH FOR FUTURE GENERATIONS

LOS ANGELES, CA (May 11 , 2004) – Seventy-year-old Trudi Butts is passionate about participating in clinical trials. Her enthusiasm stems from something unexpected that occurred while she was participating in a clinical trial in 1996. Laboratory tests done as part of a study on estrogen confirmed that she had Hepatitis C, a potentially life-threatening liver condition she didn't know she had. Further tests suggested that she probably contracted the disease from a blood transfusion she received almost 30 years earlier. She considers that unrelated laboratory discovery to be blessing that helped fuel her current attitude about clinical studies.

Recently she learned about Cedars-Sinai's Women's Health Research Registry™, an ongoing project of the Cedars-Sinai Medical Center Women's Guild, which expects to enroll for clinical research more than 10,000 participants over the next five years. The registry has been established in an effort to close the gap in the under-representation of women in clinical research. "I filled out the questionnaire immediately and sent it in, as it is a wonderful opportunity to make a significant contribution to the body of knowledge that results from clinical trials," she said. She hopes her enrollment will persuade other women – especially African-Americans like herself – to participate in clinical trials.

Clinical trials are research studies that test new scientific ideas, drugs or treatments. For many years they didn't include women because it was assumed that if a treatment worked for men, it would work the same way for women. It's been just in the last 10 years that scientists have begun to uncover significant biological and physiological differences between the sexes.

According to C. Noel Bairey Merz, M.D., Director of the Registry, the Women's Health Program and the Preventive and Rehabilitative Cardiac Center at Cedars-Sinai, "Gender-based research is showing evidence that drugs or diseases may affect people differently based on their sex and that some drugs or therapies may not be as effective in women as in men. Cedars-Sinai's Women's Health Research Registry™ aims to bring about a greater balance in the numbers of male and female trial participants in clinical trials."

There are more than 600 research projects underway at Cedars-Sinai's Burns & Allen Research Institute. Dr. Bairey Merz is Chair of a national, multi-center study called Women's Ischemic Syndrome (WISE) that received its initial funding in 1997 from the National Institute of Health's National Heart, Lung, and Blood

Institute. The study is designed to determine if previously accepted information gleaned from research conducted on men with coronary artery disease is useful in diagnosing women with heart disease.

“We’re looking for women with varying backgrounds, with or without current medical conditions, who are willing to consider participating in research studies,” says Dr. Bairey Merz. “Women represent 51% of the population yet, surprisingly, we know very little about their health and aging. The registry will allow qualified investigators to identify potential participants for their studies and, in the long term, will contribute to the future of medicine,” she says.

Many common health conditions experienced by both women and men are being managed by treatments that were developed and tested mostly in men, Dr. Bairey Merz adds. This is noteworthy in light of current data showing that: Heart disease kills 50,000 more women than men each year; women smokers are more likely to develop lung cancer than men smokers; and three out of four people suffering from autoimmune diseases such as multiple sclerosis, rheumatoid arthritis, and lupus, are women.

Women who volunteer to participate in the Registry are asked to complete a questionnaire that includes a brief medical and lifestyle history that is used to evaluate their current medical condition (if any) and to match their information for ongoing and future research studies. Personal information, such as a woman’s name, is removed from the medical information and kept separate for confidentiality purposes.

“What we call ‘identifiable information’ is not made public, but shared only with researchers who are investigating diseases or conditions that may impact women,” explains Karen Nosakowski, research coordinator. “Only after the registrant consents is her ‘identifiable information’ given to the researcher.”

There are several types of clinical trials, Nosakowski explains. Some are carried out with healthy participants and others enroll only patients with certain problems or conditions who may be helped by the treatment they receive. Some are aimed at prevention, while others look at new or alternative treatments, ways to detect specific diseases or procedures that could be used to diagnose diseases more accurately. The U.S. Food and Drug Agency regulates clinical trials and gives investigators permission to conduct tests under strict regulatory conditions.

Some women, Nosakowski says, want to participate in clinical studies because they have a strong family history of a particular disease or condition. Others do it purely for altruistic reasons. Blake Sakow, in her late 20’s, is a marketing consultant with an in-home care company for senior citizens. She was intrigued by the idea of a research registry geared for women. “My mother suffers from fibromyalgia (a form of rheumatism) and there’s so little known about it. I hope my participation in the Cedars-Sinai Research Registry™ will in some way help her and maybe myself later along the way.”

Another Registry participant’s interest was piqued after hearing Dr. Bairey Merz cite several studies showing that women often don’t receive the same levels of preventative or symptom-related medical treatment as men. Carmen Adams enrolled in the Registry in March, even though she doesn’t have a family history of any disease. “I have three daughters. That’s reason enough,” she says.

“We want our participants to feel that they are helping to find the answers for important questions in medicine,” Dr. Bairey Merz adds. “By encouraging more women to participate in clinical trials, we’re insuring that future research is available for both genders.” To enroll in the Registry or for more information, contact Karen Nosakowski at the Cedars-Sinai Women’s Health Resource Center at (310) 423-9224.

###

If you have received this news release in error and do not wish to receive future advisories, or if they should be directed to someone else in your organization, please call 1-800-396-1002. Alternatively, you may fax your updated information or your request for removal from our list to 808-263-3364 or e-mail it to sandy@vancommunications.com.