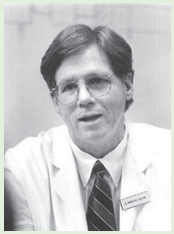
ABOUT THE RESEARCH TEAM

Mark H. Greene, M.D., is the lead investigator for the study and Chief of the NCI Clinical Genetics Branch. He has been caring for and studying patients with familial and hereditary cancers for 25 years.

W. Marston Linehan, M.D., Ph.D., is the Chief of the NCI Urologic Oncology Branch. He is one of the world's leading authorities on hereditary cancers arising in the genitourinary system.



Larissa Korde, M.D., M.P.H., is board certified in internal medicine and medical oncology, with special training in epidemiology. She has a major research interest in cancer prevention in persons at increased risk of malignancy, and is the lead clinical investigator for the Familial Testicular Cancer Study.

Christine Mueller, D.O., is board certified in Family Medicine and Medical Genetics. She has clinical experience with a diverse spectrum of genetic diseases, and is responsible for the dysmorphology component of the Familial Testicular Cancer study.

Mary Lou McMaster, M.D., is board certified in internal medicine and medical oncology. She has specialty training in clinical genetics as well. Her special interest is studying cancer-prone families.

FOR MORE INFORMATION

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

National Cancer Institute

Clinical Genetics Branch*

Division of Cancer Epidemiology and Genetics

Urologic Oncology Branch

Center for Cancer Research

Familial Testicular Cancer

* Saving lives by conquering cancer through research in clinical cancer genetics

Purpose

The National Cancer Institute (NCI) is studying families with multiple cases of testicular cancer, the most common form of cancer in young men ages 15 to 35.

If testicular cancer runs in your family, NCI invites you and your family to discuss joining the study, in order to help us learn more about this disease. The study's purpose is to:

- Find the gene or genes that cause this type of cancer to occur in families
- Describe the clinical features of familial testicular cancer
- Explore whether families prone to testicular cancer are at greater risk of other types of cancer
- Examine emotional issues within families that are at higher risk of testicular cancer
- Develop better health care choices for members of high-risk families

Who Is Eligible?

To participate, a family must have one of the following:

- Two or more men in the family with a history of testicular cancer
- One family member with cancer *in both testicles*, also called "bilateral testicular cancer"
- One family member with testicular cancer who is a member of a set of genetically identical brothers, such as twins or triplets

Parents, siblings and children of affected family members, along with any other blood relatives who are genetically linked or who have another form of cancer, may also join.

Wives of men enrolled in the study are welcome to join if their children, ages 12 and older, are participating.

Participating in Research

Those who join the study will be asked to:

- Provide blood sample or cells rinsed from the inside of the cheek for genetic studies which may help us find the gene or genes which cause familial testicular cancer
- Provide personal medical and family history information, and data on attitudes and feelings related to being in a family where several relatives have had this type of cancer
- Give consent to obtain past medical records for cancer and related illnesses

Since the genes that increase the risk of this type of familial cancer have not yet been discovered, clinical genetic testing is not part of the study. If our research finds one of these important genes, then interested participants may be able to have formal genetic testing, either as part of this study or through an additional study.

Some participants will be offered the opportunity to visit the NIH Clinical Center at no cost to them for more detailed clinical, genetic and laboratory studies aimed at finding other factors which might contribute to cancer risk among family members.

Although treatment is not part of this study, treatment options will be discussed with participants. NCI will also provide assistance in establishing care with appropriate physicians as needed. Study participants will remain under the care of their primary doctors while participating in the study.

Continuing the Dialogue

Participants and families will be asked to complete a yearly follow-up form in order to update medical and cancer information.

Participants in the study will be able to ask questions and to stay in touch with the research team.

Information that would change a patient's current medical treatment or screening for cancer will be shared with participants. The overall findings of the study will be provided when the analysis is completed.

Other Details

Confidentiality. NCI is required by Federal law not to reveal any information that is collected from study participants to anyone other than persons directly involved with the study. No personal identifying information will be released or published.

Costs. All study-related medical expenses and travel costs to the NIH Clinical Center for participants and immediate family members are paid by NCI.