Welcome to the PROGRESS Report!

Greetings from the Prostate Cancer Genetic Research Study! We are pleased to be sending you the first annual PROGRESS Report. The study is moving forward with great speed and success, thanks to all of you. Through this newsletter, you will be kept informed of the research to which you have so generously contributed.

How much PROGRESS has been made?

The PROGRESS study began recruitment in July of 1995. The big kick-off took place when Dr. Leroy Hood, Dr. Stuart Holden, Michael Milken and General Norman Schwartzkopf appeared on the Larry King Live show on November 13, 1995. The program was so well received by American and international audiences that it was repeated two weeks later. By the middle of December, almost 4,000 calls had come into the PROGRESS offices. To date, almost 400 families have been invited to join PROGRESS and the study continues to enroll new families.

We were surprised to see that the show was broadcast as far away as Brazil, Nigeria, Istanbul and Singapore! We have also been pleased to hear from many volunteers through the information superhighway - otherwise known as the Internet. The map on the back of this newsletter shows where PROGRESS participants are located around the world.

What is done with the PROGRESS blood sample?

Each willing participant with prostate cancer and other selected family members, including some women, are asked to provide a blood sample for this research. No testing of PSA (prostate-specific antigen) level is done on any of these samples. The samples, rather, are used to obtain DNA, the genetic information of each individual. The DNA from members of your family with prostate cancer are compared to the DNA from your family members without prostate cancer to try and identify places on your chromosomes likely to have prostate cancer genes.

By comparing data from your family to data from several hundred other families participating in PROGRESS, we hope to identify the genes that cause prostate cancer.

How is participant information kept confidential?

The PROGRESS study procedures have gone through careful Institutional Review Board examination and approval to guarantee the rights to privacy and confidentiality of human subjects, as mandated by the National Institutes of Health. Each participant in PROGRESS is assigned a unique study identification number. This study number is used on the blood samples, not an individual’s name. Even the scientists working with your DNA have no access to identifying information such as name or address. Your name and address are used only for the purpose of contacting you regarding the study, and are never released to anyone outside the PROGRESS study staff.

When will there be results from PROGRESS?

As of May 1996, we have begun the search for the inherited genes that may cause prostate cancer by looking at the DNA from blood samples of some participating families. Once these genes are identified, scientists will still need to study how the genes involved in the development of the disease work.

There are so many questions to be answered about prostate cancer and genetics. It will take time. We hope that this study will move quickly toward finding the answers. A better understanding of the genes involved in prostate cancer will help us develop better ways to diagnose cancer earlier, develop more effective treatments, and potentially prevent the disease.

We thank each of you for being a part of PROGRESS. We are always interested in hearing from you. If you have any questions about the study or any news to report, please feel free to call us at 1-800-777-3035. Again, we send our gratitude to you and your family for making PROGRESS happen.
Who is asked to join *PROGRESS*?

Families with three or more men diagnosed with prostate cancer are invited to participate in *PROGRESS*. Also, certain families with men who have been diagnosed at a relatively young age with prostate cancer are asked to join the study. In these families, men who have been diagnosed with prostate cancer and their brothers are invited to participate. Other family members asked to participate are different for each family. Certain uncles, cousins, and sons may be asked to join the study since they can provide important information about the family.

Some women are also asked to participate in *PROGRESS*. Women cannot develop prostate cancer because they do not have a prostate gland. However, both women and men can carry and pass on the genes that may cause prostate cancer to develop. This is why we ask for help from some female relatives of the men in the study who have had prostate cancer.

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Who is on the *PROGRESS* team?

*Fred Hutchinson Cancer Research Center:*

- Janet Stanford, Ph.D. - Epidemiologist - Principal Investigator
- Elaine Ostrander, Ph.D. - Molecular Geneticist - Principal Investigator
- Gail Jarvik, M.D., Ph.D. - Geneticist
- Susan Brandzel, M.P.H. - Study Manager
- Kris Wicklund, Ph.D. - Study Manager
- Peter McDonnell, B.M. - Program Assistant
- Suzanne Kolb, B.A. - Program Assistant
- Michael Brannan, B.S. - Program Assistant
- Laurie Hunter, B.S. - Word Processor
- Cassie Neal, B.S. - Lab
- Neil Wiegand - Lab
- Mark Gibbs, Ph.D - Lab