Dear PROGRESS Participants,

We have some exciting news to report from our search to understand why prostate cancer occurs within some families. As you know, we launched the Prostate Cancer Genetic Research Study in 1995 with the goal of identifying inherited genes that contribute to the development of prostate cancer in several men from the same family. We have recently found a region on the short arm of chromosome 1 (1p36) that may harbor a gene responsible for hereditary prostate cancer. Based on linkage results, it appears that this specific location on chromosome 1 may be involved in a small subset of families with both prostate cancer and brain cancer. We estimate that a mutation in this gene may be present in only a small proportion of hereditary prostate cancer families. This is the first significant finding from the PROGRESS study, and we wanted participants to be the first to know about the results.

A published paper of these results will appear in an upcoming issue of the American Journal of Human Genetics. This scientific advance would not have been possible without the participation and dedication of you and your family. We are truly grateful for the ongoing help from all PROGRESS families, who are making this important research possible.

To understand what this discovery means we can use an analogy. Finding the location of a possible gene on the short arm of chromosome 1 is like focusing our attention on a particular state such as Washington State, but not knowing the city, town or street address where this specific gene may be located. Since we have only identified a large region that looks suspicious, there is still a lot of work to be done.

We must wait to see if other studies confirm these results. If confirmed, a major effort to identify this gene will begin. This will be a tedious and time-consuming effort, but it is our ultimate goal to identify this gene and other genes involved in prostate cancer.

Because no gene for prostate cancer has yet been found, there are no tests that can be done to determine whether or not individuals in your family are carriers of this or any other prostate cancer gene. We will continue to update you through our newsletter of any new advances in identifying prostate cancer genes. The future identification of specific hereditary prostate cancer genes should allow us to develop new strategies for the diagnosis, treatment and prevention of the disease.

We know that many of you may have questions about these results. In this issue of the PROGRESS Report, we have tried to answer some of these questions. If you have additional concerns, please contact us. We are very interested in you and your family, and we are always pleased to hear from you. Again, we thank you for your contribution to this important discovery and for all that you are doing to help us make progress against prostate cancer.

Sincerely yours,

Janet Stanford, Ph.D.
Principal Investigator

Suzanne Kolb
Study Manager

We still need you! Although we have received 89% of the study materials from participants, we are still hoping to receive 215 outstanding questionnaires. If you haven't completed your forms, it's not too late to send them in or call to request a second copy. Please contact us with any questions or family updates. We would also like to take this opportunity to wish you and your family a joyous and peaceful holiday season.

FHCRC - The PROGRESS Study
1100 Fairview Ave N; MW 814
P.O. Box 19024
Seattle, WA 98109

Call us toll-free at 1-800-777-3035
Or write to us using e-mail at: progress@fhcrc.org

Catch Us on the Web!
www.fhcrc.org/science/whs/proggress_study/
LOCATING OTHER POSSIBLE PROSTATE CANCER GENES

Prostate cancer is a complex disease, and it probably involves multiple genes. In addition to our recent finding on chromosome 1p36 (tentatively called “CAPB”), three additional locations for prostate cancer genes have been reported by other groups. None of the genes in any of these regions has yet been identified, but several groups are working on these areas. Here is a brief summary of the prostate cancer regions that have been identified so far:

1q24-25, known as “HPC1” – Located on the long arm of chromosome 1, and based on analyses of 91 families with prostate cancer from the U.S. and Sweden, this was the first reported region associated with prostate cancer in families.

1q42.2-43, known as “PCAP” – Also located on the long arm of chromosome 1, this study included 47 French and German families with prostate cancer and the results were reported in June, 1998.

Xq27-28, known as “HPCX” – Located on the X chromosome, these results are based on a combined group of 360 families with prostate cancer from North American, Finland, and Sweden. This is the first prostate cancer region which may be passed exclusively from mother to son, since all men receive their X chromosome from their mother.

The PROGRESS team has been trying to confirm these results in addition to locating new suspicious regions. Our results on HPC1 provided very little evidence that this region is linked to prostate cancer in our group of families. We are currently analyzing our data for the other two regions (PCAP and HPCX). We will report our findings to you in a newsletter as soon as the analyses are completed and published.

QUESTIONS AND ANSWERS ABOUT OUR FINDINGS

1. What does this finding mean for me and my family?
These results mean that we are getting closer to finding out about the genetics of prostate cancer. Right now we don’t know exactly how important this finding will be for families with prostate cancer. What we report is a suspicious area of interest – not a gene. Finding the gene at this point will be like finding a needle in a haystack, but at least now we have a clue where to look.

2. Do I have this gene? Where can I be tested for this gene?
Currently, there are no meaningful individual results because no gene has been identified. The results describe a comparison of one group of families to another group of families. The statistical methods we used do not measure individual results. It will take time and further research to identify the exact location and the gene involved, and even longer for a test to be developed, approved, and made available.

3. When the gene is found in the future, will you tell me if I have it?
No, we will not be able to provide any individual results from PROGRESS.

4. Why don’t you provide individual results?
We are a research facility, not a clinical genetics laboratory. When a prostate cancer gene is located and a genetic test becomes available, only approved labs who are monitored with strict quality controls can provide the information you will need. We are not able to provide this level of individual testing or the necessary genetic counseling to help you interpret the results. We will continue to update you through newsletters as our research continues. As soon as a test is available, you will be one of the first to know. When it is available, we will help you to locate a genetic counselor in your area who can help you to be tested if you choose to do so.

5. How important is this gene?
We estimate this region may account for a small proportion of inherited prostate cancer (perhaps 5 to 10%), but much more research is needed to know the true importance of this region.

6. Does this mean my family members are at higher risk for brain cancer in addition to prostate cancer?
No, not based on these results alone. Brain cancer is very rare and these results need to be confirmed by other researchers before we can say anything about the risk of brain cancer in families with prostate cancer. As always, if you have specific concerns about your health, please see your personal physician.

7. Was our family part of this group that was studied?
We don’t know. All identifying information is removed to protect your confidentiality and to ensure that the results are not biased by any of the personal information. We have received almost 2,000 blood samples and only about 1,000 of those are included in this analysis. Even though you have provided a sample, the information from your sample may not be included in this particular analysis.

8. Where can I get a copy of your results?
If you would like a copy of the paper describing these results, please call our toll-free number 1-800-777-3035. We will send a copy of the paper to you when it is available.