Welcome to the 10th issue of The Progress Report, a newsletter for participants enrolled in PROGRESS, the Prostate Cancer Genetic Research Study. The study has enrolled families from across North America and abroad to help pinpoint the genes that may cause hereditary prostate cancer. We hope you find the information in our newsletter to be interesting and helpful. If you have any questions about the content of this newsletter or about your participation in the study, please call us toll free at 1-800-777-3035.

A BRIEF HISTORY OF PROGRESS

We would like to welcome our newest participants by providing a brief description of how PROGRESS began. In 1995, Drs. Janet Stanford, Elaine Ostrander, and Leroy Hood began to work together to understand prostate cancer genetics. To find the genes that cause hereditary prostate cancer, they began to collect information about families that fit the definition for hereditary prostate cancer or HPC (see sidebar below for definition). In order to get the word out about our study, Dr. Hood appeared on the television talk show “Larry King Live” in November 1995 along with Michael Milken and General Norman Schwartzkopf. Mr. Milken is a prostate cancer survivor and his foundation called CaP-CURE provided funding to start the PROGRESS study. General Schwartzkopf is also a prostate cancer survivor. As a result of the television show, the PROGRESS office was overwhelmed with calls from interested people willing to volunteer for the study. In addition to the television show, information about the study was sent to healthcare providers, employers, support groups, and even posted on the Internet to find as many families as possible that fit definition for hereditary prostate cancer. As a result of these efforts, 266 families and more than 2,000 people are participating in PROGRESS.

NEW FAMILY COLLECTION EFFORT BEGINS

The study of the 266 PROGRESS families is usually referred to as a “family study” because we have collected information and blood samples from people in each family. We aimed to collect hereditary prostate cancer or HPC families. A family study of men with HPC is very helpful for finding rare, inherited disease genes. Because HPC is believed to cause less than 10% of the disease, we are also interested in finding genes that may be involved in the development of prostate cancer in men who don’t fit the HPC criteria. When prostate cancer occurs more than once in a family, such as in two brothers or a father and son, but affects fewer than three very close relatives, it is called familial prostate cancer. In addition to finding the rare genes that may cause hereditary prostate cancer, we are also beginning a project that will help to understand how important these genes may be in familial prostate cancer. The study may also help us understand the role of normal variations in more common genes in the development of prostate cancer. For the new study, we will be recontacting men who participated in an earlier study of prostate cancer conducted at the Fred Hutchinson Cancer Research Center from 1993-1997. Participants in the earlier study answered questions about whether they had a family history of prostate cancer. We are now enrolling family members of these participants. The collection of families that results from this process is called a “population-based” family study because men with prostate cancer who participated in the prior study were all residents of the same geographic area or “population base.” We hope that the information from this new study will help us understand how common genetic variations may be related to prostate cancer.

DEFINITIONS

First-degree relative – a person who is directly related to you by blood, such as your father, brother, or son.

Second-degree relative – a person who is related by blood but who is not as closely related as a first-degree relative. Examples of second-degree relatives are a grandfather, uncle, or nephew.

Third-degree relative – a person who is more distantly related to you by blood, such as a cousin or great-grandparent.

Hereditary prostate cancer (HPC) - Families with three or more first-degree relatives with the disease; OR two first-degree relatives diagnosed with prostate cancer before age 55; OR prostate cancer diagnosed in three successive generations on either the mother’s side or the father’s side.

Familial prostate cancer (FPC) – Families with prostate cancer in two first-degree relatives; OR prostate cancer diagnosed in one first-degree and two or more second-degree relatives.
The Next Step

As we mentioned in our last newsletter, we will be asking you to participate in a follow-up survey for PROGRESS participants. The survey will ask about any changes in your health or your family’s health in the time after you completed the first PROGRESS survey, as well as a few additional questions. As always, your continued participation is completely voluntary. We plan to have the first batch of surveys sent out by the end of this year. We will mail the surveys in batches through 2002, so you may not receive your survey this year. We understand many of you move to different parts of the country throughout the year and we do try to keep your address up to date. If you or your relatives are not receiving this newsletter at your preferred address, please call or write to let us know the best address at which to reach you. We want to be sure to find you when we mail your survey!

Thank You!

You may remember from previous newsletters that we contacted some participants for information about their deceased relatives. We understand that it is sometimes difficult to provide details about when and where a relative passed away.

We are very grateful for the help of those who responded to our request. The death certificates for some relatives are needed to confirm and document the causes of death.

As a result of the excellent response we received from PROGRESS participants, we have collected 258 certificates for deceased relatives. The death certificate information for these individuals will be incorporated into the analysis of the PROGRESS families to strengthen the statistical power of our study, which we hope will provide new insights into how this disease may be passed from one generation to the next.

Keep In Touch

Please contact us if you have any updates to share with us. You can reach us by:

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If you would like copies of our earlier newsletters or for additional information, please visit our website:
www.fhcr.org/science/phs/progress_study

Here are some of the faces from behind the scenes of PROGRESS

The members of our study team (from left to right) are: Liza Noonan, Statistician • Laurie Hunter, Desktop Publishing Specialist • Dr. Janet Stanford, Principal Investigator • Suzanne Kolb, National Study Coordinator • Michael Brannan, Program Assistant • Jim Works, Computer Programmer • Lori Iwasaki, King County Study Coordinator • Ric Johnston, Computer Programmer. Not pictured: Heather Riccardi, Administrative Assistant.