

Prostate Cancer: The Next River To Cross

This newsletter is an update on the study you have so generously participated in. We hope you will enjoy reading it. Please share it with your family and friends. Future newsletters will be sent. If you have suggestions or would like to contribute, please call us at 1-888-218-6157. We enjoy hearing from you!

Thanks to the 76 families and 582 individuals who are helping in the search for prostate cancer genes. Together we will succeed.

"Some things should not have to pass from generation to generation."

Prostate cancer is the most common cancer among American men. It causes more than 40,000 deaths each year. Scientists are beginning studies to explain why prostate cancer is more common in African American men than in any other group of men in the U.S. They are focusing closely on the role of inherited factors. For every 100,000 African American men, about 181 will have prostate cancer this year. Fifty-four of them will die from the disease. Howard University in Washington, D.C. has funding from the National Institutes of Health for a national study to find genes which help cause hereditary prostate cancer in African Americans.



The African American community has experienced many burdens, including higher rates of prostate cancer. Black men are twice as likely to die from prostate cancer as any other group of men. I believe that some things should not have to pass from generation to generation. Genetics is an area that holds tremendous promise for men with prostate cancer. As a prostate cancer survivor, I want to help all African American men have the ability to live and enjoy their children and grandchildren! That is why I became involved with and encouraged other urologists to be part of the African American Hereditary Prostate Cancer Study. -Isaac Powell, M.D., Prostate Cancer Survivor and Principal Investigator, AAHPC Study, Wayne State University, Detroit, MI

“An Historic Study”

“The African American Hereditary Prostate Cancer Study is indeed a significant accomplishment and a major milestone. Every step it takes and every move it makes is historic and pace-setting. Establishment of the AAHPC Study Network for this research effort is a blessing! You might say, ‘we have crossed this Jordan’, but there is always ‘one more river to cross.’ Together we will cross it too!”

Georgia M. Dunston, Ph.D.

Founding Director

National Human Genome Center at Howard University

Washington, DC



“Project is Going even Better than Expected!”

"The African American Hereditary Prostate Cancer study is groundbreaking in many ways. The study aims to un-

close collaboration between Howard's National Human Genome Center and the NIH's National Human Ge-

paid to the ethical, cultural, and social aspects of carrying out this study on an underserved population that has not always had good experiences as participants in medical research. If successful (and so far the project is going even better than expected), this is likely to be seen as a model for many other studies on other diseases."

-Francis Collins, MD, PhD

Participants Speak Out

"Yes, I will participate and will make sure all my family participates because it is about time we started doing something for ourselves that will save us. I wish this study had been around 50 years ago, maybe my father, and two uncles would be alive. I will be glad to participate because I can see this helping my future grandchildren."

*-52 year old man,
Atlanta, Georgia*

cover hereditary factors in a common type of cancer that is particularly devastating in African American males; the study has been organized so that the principal investigators are close to the community under study, and many of the PIs are African American; a

nome Research Institute undergirds the project; and careful attention is being

Francis Collins, M.D., Ph.D.

Director

National Human Genome Research Institute

National Institutes of Health, Bethesda, MD



This Research Could Also Lead to New Therapies for Prostate Cancer in African American Men

Prostate cancer is one of the most serious health disparities in the United States today. African American men are more likely to develop the disease and are much more likely to die from prostate cancer than white men. Although diet and other factors probably contribute to prostate cancer risk, family history is the most significant risk factor known. Many groups around the world are trying to identify the gene mutations or changes that contribute to the development of prostate cancer. However, there has not been any targeted recruitment of African Americans in hereditary

prostate cancer studies. We have finished the initial genetic analysis of a group of African American families at high risk for prostate cancer and are well on our way towards identifying gene mutations or changes that make men susceptible to developing prostate cancer. Of extreme importance to this group is the identification of genes that may be more common among African American men. We hope that through this work we will be able to perform simple genetic tests



*John Carpten, Ph.D.
National Human Genome Research Institute, NIH*

to determine a man's risk of developing prostate cancer. This research could also lead to new therapies for prostate cancer in African American men.

- John Carpten, Ph.D.



Curtis Pettaway, M.D. of M.D. Anderson Cancer Center talks with a patient

Families Are Forever

You can make a difference!

For yourself, your sons, and future generations!

Say "Yes" to the Hereditary Prostate Cancer Study.

If you have prostate cancer and several living blood family members with cancer, please call toll free:

1-888-218-6157 or visit our website:

http://www.nhgri.nih.gov/About_NHGRI/Dir/Prostate_Study

Ethical Issues in the AAHPC Study

The African American Hereditary Prostate Cancer (AAHPC) Study holds great promise for improving the health of African American men. However, along with the opportunities come several challenges that AAHPC Study investigators have to deal with. One of the most critical issues is the recruitment of African Americans as research participants. For various reasons (e.g. past negative experiences, cultural/religious beliefs, physicians' attitudes) African Americans have not been very eager to participate in medical research. This low level of participation could decrease the capacity of African Americans to share in the anticipated benefits of research, such as improved health. Therefore, the organizers of the AAHPC Study have taken certain steps to reduce fear and build trust with the community in order to

increase the likelihood that eligible families will participate and the commu-

nity might benefit. Perhaps the most significant step is ensuring that most of the physicians, scientists, recruiters, data managers, as well as other investigators and staff are African American, thus are more likely than others to understand and be sensitive to the concerns, needs, interests,

and expectations of community members. Many believe that this is the main reason for the success in recruiting 76 families thus far.

Another major issue, for researchers and participants, is privacy of participants' genetic and other personal information. Given the possibility that insurance companies, employers, family members, or other researchers could misuse information obtained through genetic research, the AAHPC Study has several safeguards to protect partici-

pants. For example, no personal information or individual study results are shared with any third party (including family members). Participants' files are stored in locked drawers or cabinets and are available only to study investigators and staff. In addition, only identification numbers (no names) are used on forms and other research material/information stored in files and on computers. Only the physician and study coordinator at a participant's recruitment site has access to the participant's name.

Although it is unlikely that anyone can fully guarantee privacy of genetic or other medical and personal information, the AAHPC Study in-

vestigators are committed to providing the highest level of protection possible for all participants.

Future newsletters will address other ethical and social aspects of the AAHPC Study, thereby providing additional information on some of the non-scientific issues

related to genetic research. Community outreach and education are important goals of the AAHPC Study, and are key in helping individuals to

make decisions about participation in genetic research and use of genetics healthcare services.

"I'm so glad you are doing this study - I'm so tired of seeing all my brothers die from prostate cancer"

*-77 year old woman who has had 5 brothers diagnosed with prostate cancer
Columbia, South Carolina*

"I did it because I know it will help my grandchildren."

*-58 year old man
Houston, Texas*



Charmaine D. M. Royal, Ph.D.
National Human Genome Center at
Howard University, Washington, DC



James Bennett, M.D.
Midtown Urology Surgical
Center

Frequently Asked Questions

Q: What is hereditary prostate cancer?

A: Hereditary prostate cancer is caused by changes in genes that are passed down in families. It usually occurs in several family members and often starts earlier than most prostate cancer (often before age 65).

Q: How do I know if I am at risk for hereditary prostate cancer?

A: Men who have several family members with prostate cancer and/or a family member who had prostate cancer at an early age may be at risk for hereditary prostate cancer.

Q: I do not know if I have blood family members with prostate cancer.

What can I do?

A: Cancer is not easy to talk about. Knowing your family history is important. Talk to your father, uncles, grandfathers, and cousins about your family history.

Q: Do all men with prostate cancer have *hereditary* prostate cancer?

A: No, most (about 90%) prostate cancer is due to other causes.

Q: When genes are found which increase risk for prostate cancer, how will that help men like me, my sons, and grandsons?

A: We believe it will lead to better treatment and maybe even to prevention.

Q: Why are African American families being asked to help?

A: For reasons that are not clearly understood African American men have the highest rates of prostate cancer in the United States. African Americans are needed to help find the solutions.

Q: Is it too late to enroll in this study?

A: No, it is not too late! We continue to accept new families. Contact the center nearest you (see page 7) to find out how to enroll or call [1-888-218-6157](tel:1-888-218-6157)



“I am looking for something good to come out of this study.”

Howard Barrett, 43 y.o. and sons, Clifford, 4 y.o. and Phillip, 9 months., South Carolina

prevent prostate cancer. I would like for my boys to grow up and not have to worry about prostate cancer. I am looking for something good to come out of this study.”

Howard and his two brothers as well as their father have all

been diagnosed with prostate cancer. Howard and eleven other family members participated in the nationwide African American Hereditary Prostate Cancer Study designed to find the gene(s) that cause hereditary prostate cancer.

“I was shocked when I found out I had prostate cancer” says Howard, a former USC football player. “I always thought I was in perfect health for a man. But I kept praying and hoping, and things worked out. I feel good now. I have my weight down, I don’t eat a lot of fat foods, and I exercise regularly.”

“I feel good telling other people about prostate cancer. I am just sorry that prostate cancer has been kept a secret for so long. We can save lives by talking about it.”

“If there is something that I can do so that my boys won’t have to worry about prostate cancer, I want to do it” says Howard Barrett, who was diagnosed with prostate cancer in 1997. “I want them to find a cure or a way to do something to

Participants Speak Out

“I hope my participation in your research will be of help and lead to the cure for prostate cancer that’s taking so many men. God bless you and your work.”

-74 year-old man,

Chicago, Illinois

Families are Forever

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Site Locations and Contact Numbers



Location: Detroit, MI
Karmanos Cancer Institute
Wayne State University
(313) 745-8486

Project Director: Isaac Powell, M.D.
Project Coordinator: Edna Johnson



Location: Houston, TX
M.D. Anderson Cancer
Center
(713) 792-3250

Project Director: Curtis Pettaway, M.D.
Project Coordinator: Pam Roberson



Location: Atlanta, GA
Midtown Urology Surgical
Center
(404) 881-0966

Project Director: James Bennett, M.D.
Project Coordinator: Laura Kososki, M.D.,
and Carrie Jones



Location: Chicago, IL
Columbia Michael Reese
Hospital and Medical Ctr.
(312) 791-2514

Project Dir.: Srinivasan Vijayakumar, M.D.
Project Coordinator: Carol Meegan



Location: Columbia, SC
School of Public Health,
Univ. of South Carolina, &
School of Nursing, Univ. of
Louisville

(803) 777-5192 or (888)778-5192 toll free
Project Director: Sally Weinrich, Ph.D.
Project Coordinator: Louise Faison-Smith



Location: New York, NY
Harlem Hospital
(212) 305-5524

Project Director: Gerald Hoke, M.D.
Project Coordinator: Raul Mejia, M.D.



Location: Washington, DC
Howard University
Cancer Center
(202) 865-1314

Project Dir.: Chiledum Ahaghotu, M.D.
Project Coordinator: Michelle Johnson



Location: Chicago, IL
Prairie Medical
University of Illinois
(312) 842-4400

Consultant: Terry Mason, M.D.

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To order a free video of "The Next River to Cross" please contact Dr. Lowry of the African American Hereditary Prostate Cancer Study at 1-888-218-6157

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[Http://www.nhgri.nih.gov/About_NHGRI/Dir/Prostate_Study](http://www.nhgri.nih.gov/About_NHGRI/Dir/Prostate_Study)

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