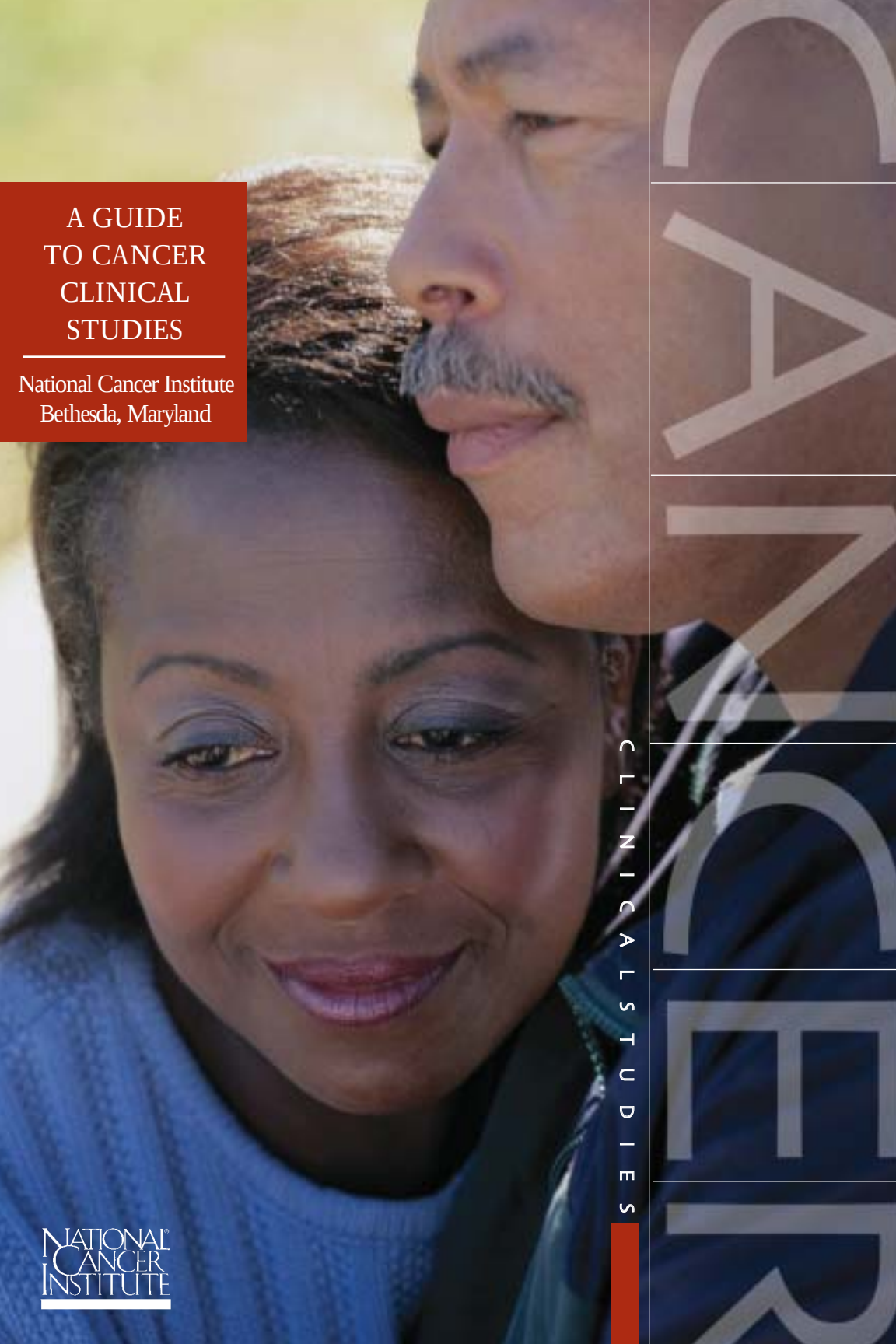
A GUIDE TO CANCER CLINICAL STUDIES

National Cancer Institute
Bethesda, Maryland



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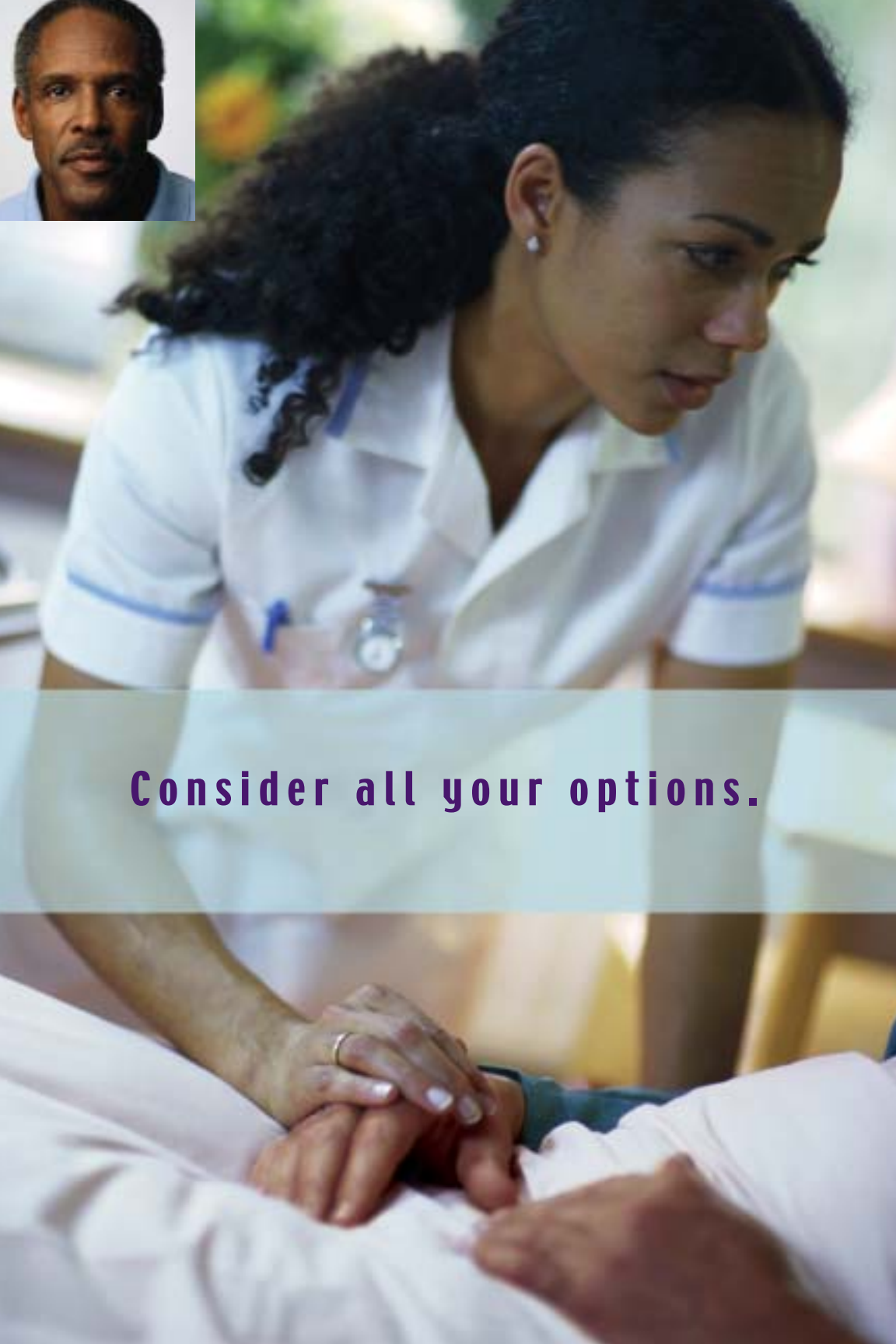

Consider all your options.

Cancer is a serious disease. About 1,500 Americans die from cancer each day. But today more people than ever before survive cancer. Many people who get cancer go on to live full lives.

Still, cancer strikes African Americans harder than other ethnic groups. Look at these facts:

- African Americans have the highest overall cancer incidence and death rates of any racial/ethnic group in the United States.[1]

- For all cancer sites, African Americans are less likely than Whites to survive 5 years after being diagnosed with cancer.[2]

- For all cancers combined, African American men have a 20% higher incidence rate and a 40% higher death rate than White men.[3]

Clinical studies test new ways to prevent, diagnose, and treat cancer. They have led to both improved survival rates and fewer symptoms in people with cancer. What doctors learn from clinical studies will help future generations of African Americans and may even help you or someone you know.

This booklet will tell you more about clinical studies that are available at no charge at the National Cancer Institute in Bethesda, Maryland.

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[1] Surveillance, Epidemiology, and End Results Program, Cancer Health Disparities, April 23, 2003.
[2] Surveillance, Epidemiology, and End Results Program, 1973-1999. Division of Cancer Control and Population Sciences, National Cancer Institute, 2002.
[3] Surveillance, Epidemiology, and End Results Program, 1973-1999. Division of Cancer Control and Population Sciences, National Cancer Institute, 2002.

WHAT ARE CLINICAL STUDIES?

Clinical studies test new ways to fight cancer in people. This is how better methods to treat and prevent cancer are discovered.

WHY ARE CANCER CLINICAL STUDIES IMPORTANT?

A clinical study is one of the final stages of a long and careful cancer research process. Studies are done with patients with cancer or at higher risk for developing cancer to find out whether promising approaches to cancer prevention, diagnosis, and treatment are safe and effective.

Most standard treatments and drugs used for cancer today were first tested in clinical studies. New clinical studies look for even better ways to fight cancer. To make sure that new treatments work the same for everyone, and to be sure everyone has the same access to these options, it is important for people of all races, ethnicities, and ages to take part in clinical studies.

Insist on quality treatment.

Make a difference.

WHY SHOULD YOU PARTICIPATE IN A CANCER CLINICAL STUDY?

- If a new treatment has an effect on cancer, you might be among the first to benefit.
- You will receive individual care by doctors, nurses, and other health care professionals who are experts in cancer treatment. These professionals will closely monitor your health and any side effects.
- The National Cancer Institute conducts some of the most novel medical research in the country.

WHY SHOULD AFRICAN AMERICANS PARTICIPATE IN A CANCER CLINICAL STUDY?

- African Americans should have equal access to clinical studies and promising new treatments. Everyone has the right to know and understand every health care option available, including clinical studies.
- Taking part in clinical studies helps improve cancer care for all people. When African Americans take part in clinical studies, it helps make sure that treatments work for everybody.
- Participation gives African Americans a chance to contribute to medical knowledge that could help save lives in future generations. Taking part can make a difference for the African American community.

ARE CLINICAL STUDIES SAFE?

Some African Americans don't trust clinical studies, because of abuses that happened in the past. But today there are ways to protect people who participate in clinical studies.

The law says that people with cancer who wish to join a clinical study must get all the facts about the treatment and possible side effects before they join. This is part of what is called the informed consent process. The process helps people decide whether to take part in a study by giving them information. It begins with a doctor or nurse on the research team explaining the treatment, possible risks and benefits, and the rights of study participants.

You will then be given an informed consent form to review, which also contains information about the study. If you decide to join, you will sign the form. **Signing the form does not take away your rights. You keep your rights, including your right to leave the study at any time.**

DO CANCER CLINICAL STUDIES USE PLACEBOS?

Some people worry that they will receive a placebo (sugar pill) instead of treatment if they take part in a clinical study. But people never get a placebo if a standard treatment exists for their cancer. And placebos are very rarely used in cancer treatment studies at all. If you are considering a clinical study where you might receive a placebo, you will be told about this possibility before you join the study.

Get all the facts.

Decide what is best for you.

HERE ARE SOME IMPORTANT THINGS TO KNOW BEFORE YOU DECIDE TO TAKE PART IN A CLINICAL STUDY:

- You, your family, and your doctor will get all the facts (good and bad) about the study before you decide to participate.
- You can change your mind and withdraw at any time during the study.
- Institutional review boards—panels of expert doctors, patient advocates, and spiritual leaders—review and approve the clinical study before you are asked to join. They make sure that your safety is protected.
- Highly trained medical professionals check the medicines, treatment, and care to prevent and discover any problems.
- Your safety and well-being are the research team's main concern. If the treatment is decided to be too risky or if you do not benefit, the treatment will be stopped. If this happens, you can discuss your other options with the research team or with your usual doctor.

WHAT ARE THE COSTS?

The National Cancer Institute (NCI) in Bethesda, Maryland, provides cancer care at no charge to people who are enrolled in a clinical study. But you should keep your current insurance to cover medical care not covered under the study. Once the study is complete—or if you choose to leave—you will return to your usual doctor for care. Cancer care at NCI does not replace routine care you receive from your doctor.

HOW CAN I DECIDE WHETHER OR NOT TO PARTICIPATE IN A CLINICAL STUDY?

The decision is completely up to you. Talk to your doctor, family, and friends, and consider the possible benefits and risks.

Remember that if you decide to participate in a clinical study, you might contribute to medical knowledge that could help save lives in future generations. You can make a difference for the African American community and possibly for yourself.

The following National Cancer Institute (NCI) services can give you more information on clinical study possibilities.

Clinical Studies Support Center
1-888-NCI-1937
http://bethesdatrials.cancer.gov

The Clinical Studies Support Center (CSSC) provides personalized assistance to callers who are interested in clinical studies taking place at the National Cancer Institute in Bethesda, Maryland.

Cancer Information Service
1-800-4-CANCER
TTY: 1-800-332-8615 (for people who are deaf or hard of hearing)

The Cancer Information Service provides up-to-date cancer information and information on clinical studies sponsored by the National Cancer Institute as well as some studies conducted by independent researchers.

National Cancer Institute Web Site
www.cancer.gov

The Clinical Trials section of the Web site has information on clinical studies taking place now. The Cancer Information section has information on cancer treatment, screening, prevention, and supportive care. NCI is part of the National Institutes of Health, a government agency.

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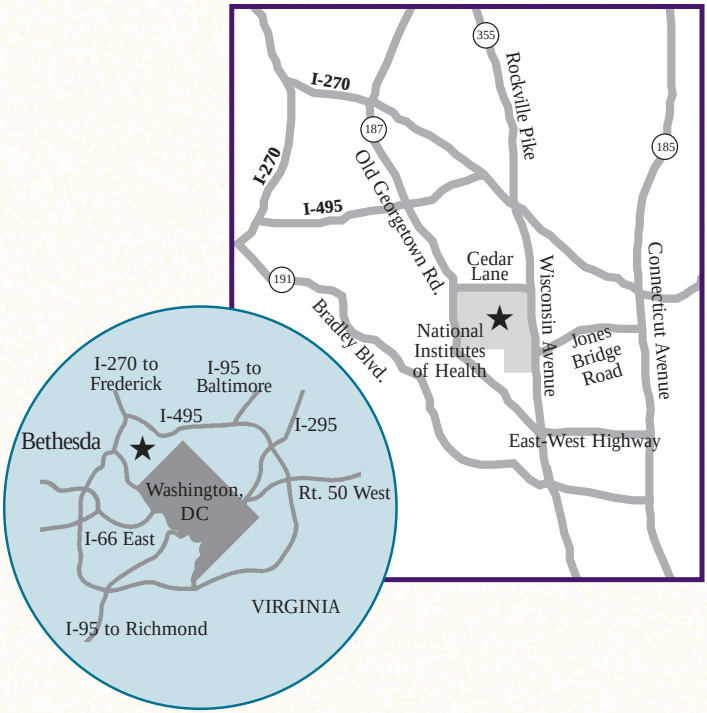
NOTES

WHERE IS THE NATIONAL CANCER INSTITUTE?

The National Cancer Institute is located just outside of Washington, D.C., on the campus of the National Institutes of Health in Bethesda, Maryland. If traveling by car, you will find the campus just south of Cedar Lane between Rockville Pike and Old Georgetown Road. If you join a study, almost all of your care will be provided in the Clinical Center (also called Building 10). Patient parking is located under the Clinical Center. If traveling by public transportation, you should take the Red Line Metro to the Medical Center stop.



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