Welcome to the third edition of the Long-Term Follow-up Study newsletter. In this issue we feature an article on the role of genes in cancer and similar illnesses. We also provide you with some facts about an important health concern, hepatitis C.

This is a very exciting year for the Study, as we finish recruiting the members of our cohort (a term for the total group of participants in the study). Currently, over 13,650 people throughout the United States and Canada are participating in the Long-Term Follow-Up Study, and we have already begun to analyze the valuable information you have given us. Later this year we plan to begin publishing our findings and we will, of course, keep you informed when we do.

**New smoking study**

As we reported in last year’s newsletter, about 28% of study participants over the age of 18 have smoked tobacco. Researchers at the Dana Farber Cancer Institute in Boston, together with the Long-Term Follow-Up Study team, have received a grant from the National Cancer Institute to look at the health practices (including smoking habits) of our study participants. In connection with this, some of you may receive brief phone calls from individuals with similar health backgrounds to talk about your health and health-related behaviors. Participants will be able to share their thoughts and concerns about either continuing to smoke or quitting smoking. If you are interested in providing your opinions and thoughts about health-related issues, please call Dr. Ann Mertens at 1-800-775-2167.
Genes and the fight against cancer

By participating in the Long-Term Follow-Up Study, you are making an important contribution to the fight against cancer, leukemia, and similar illnesses. The information you have already given us will help doctors and scientists in their efforts to create new and better treatments and to identify the health-related issues of having been successfully treated for one of these diseases.

There are many causes of cancer, most of which are not known. What is known is that some genetic factors in people can make it more likely for them to develop cancer. By comparing the genetic material (DNA) from a great many people, scientists can gather clues about which genes might increase a person’s risk.

Some facts about cells, genes, and DNA

**Cells** are the basic units of the human body, and of all living things. Our bodies are composed of brain cells, bone cells, blood cells, and other types of specialized cells that make up our organs, our muscles and all our other physical systems. The nucleus of each cell contains the genetic material that makes us unique.

**Chromosomes.** In the nucleus of each cell, genes are found on thread-like structures called chromosomes. Each cell (except for sperm and egg cells) has 46 chromosomes arranged in 23 pairs. We get one of each pair from our fathers and one from our mothers. Chromosomes are made of DNA and protein. The DNA is what carries our unique “genetic code”, a blueprint for life.

**DNA** is a very long, tightly packed molecule made up of individual units, or building blocks, called nucleotides. The nucleotides are strung together in pairs on two long chains and it is this pairing that forms the DNA double helix. There are about three billion nucleotide pairs in each of our cells. Unless you have an identical twin, the pattern they are arranged in is unique to you.

Finally, a gene is a segment of a DNA molecule that contains instructions for the body to produce a particular protein. The protein then determines or helps to determine a physical trait. Humans have about 100,000 genes. Some genes produce noticeable traits, like hair or eye color. Others produce traits that can’t be seen, like our blood type. Scientists believe that each person’s unique genetic code also plays a part in shaping more complex traits, such as intelligence. And, it can influence our susceptibility or resistance to certain diseases, including cancer.

“Banking” DNA

In collaboration with the Long-Term Follow-Up Study, researchers at the University of Minnesota are planning to create a library, or bank, of DNA from survivors of cancer, leukemia and similar illnesses. DNA from this bank would be made available to scientists who are seeking to discover which genes might be involved in the development of cancer and similar diseases (and their complications). An example of how the Univer-
As a member of the Long-Term Follow-Up Study cohort, you may be asked to donate some cells for the DNA bank. Cells can be collected very easily from the inside of the mouth by rinsing vigorously with a mouthwash, such as Scope, for 30 to 60 seconds. If we ask you to donate cells for the DNA bank, we will send you a sample of mouthwash and a collection bottle to mail your cells back to us. Alternatively, if you had surgery to remove a tumor, we may ask your permission to acquire some of the tumor tissue from the hospital where you had your surgery for storage in the bank.

As always, you have the right to decide whether or not to participate. If you do donate cells, they will be labeled only with a number—the researchers who study your DNA will not know who you are. Your DNA will not be altered in any way or used for any purpose other than cancer research. Your participation in the DNA bank, like the other aspects of your participation in the Long-Term Follow-Up study, is totally confidential.
What is HEPATITIS C?

Hepatitis is an inflammation of the liver. Hepatitis A and B are the best-known types. Others are called hepatitis non-A non-B (NANB). The most common type of hepatitis NANB is hepatitis C. This virus invades and destroys liver cells. The body can usually overcome the virus, but chronic (long-term) infection may occur. The following article is from the After Completion of Therapy (ACT) Clinic at St. Jude’s Reserach Hospital, Melissa Hudson, M.D., director.

How does it start?

The hepatitis C virus is carried by the blood. Many infections are caused by needle sharing among drug users. Transfusions now cause fewer than 5% of hepatitis C infections. However, the blood supply was not routinely screened for hepatitis C before 1992. Anyone who received a blood transfusion before that time is at risk and should request a screening blood test from their family doctor or healthcare provider. The virus can also be spread through other kinds of blood contact, hemodialysis, and organ transplantation. The infection may possibly be transmitted through sexual contact, and from mothers to infants before birth. In 40% of cases, the source of infection is not known.

How serious is hepatitis C?

The infection is usually short and mild. However, about half of patients continue to be infected even though they may feel well. Some develop serious long-term effects. About 20% of patients develop scarring of the liver (cirrhosis), and a very few develop liver cancer.

What are the signs of hepatitis?

A few weeks or months after infection, patients may feel tired, lose appetite, feel pain or tenderness in the abdomen, or have dark urine or yellowing of the skin and eyes. Many patients have no symptoms at all, but routine blood tests may reveal the infection. A positive test may mean acute (initial), chronic (long-term), or past infection. A few false positive tests are caused by other conditions. To know exactly what is wrong with you, your doctor needs other information in addition to this test. This test is not related to AIDS.

Preventing the spread of infection

If you should become infected, use the following precautions:

- Others should not use your razor, toothbrush, nail clippers, or any item that may come in contact with blood.
- Clothing, sheets, or towels with blood stains can be washed with the family laundry. Add one cup of bleach to the wash load.
- It’s OK to share your silverware, glasses, and dishes. Casual kissing is not a problem. Urine and saliva are a danger only if they contain blood.
- It is not known if hepatitis C can be transmitted sexually, but about one-third of spouses married for 20 to 50 years become positive for the virus. Sexual intercourse should be avoided if there is any genital bleeding, such as menstrual periods, genital ulcers, or cuts. Routine condom use may be the wisest course for couples beginning a new sexual relationship.

What can be done about hepatitis C?

During the initial illness, treatment is given only for troublesome symptoms. Patients with symptoms of chronic hepatitis should ask their doctor if they are good candidates for long-term treatment programs. Antiviral therapy for hepatitis C is typically recommended only for patients with abnormalities of liver function. Anyone who tests positive for hepatitis C should be aware of other infections and health habits that are harmful to the liver. Immunization with hepatitis A and B vaccines (if you don’t already have immunity) and abstinence from alcohol will protect the liver from further injury if you have chronic hepatitis.