

QUESTIONS AND ANSWERS CONCERNING THE BERYLLIUM-INDUCED LYMPHOCYTE PROLIFERATION TEST (BE-LPT), MEDICAL RECORDS, AND THE DEPARTMENT OF ENERGY BERYLLIUM REGISTRY

What is the Be-LPT blood test?

In the Be-LPT, lymphocytes, disease-fighting blood cells that are normally found in the body, are examined in the laboratory and separated from your blood. Beryllium and other test agents are then added to small groups of these lymphocytes. If these lymphocytes react to the beryllium in a specific way, the test results are “positive.” If they do not react to beryllium, the test is “negative.”

Experts believe that the Be-LPT shows positive results in individuals who have become sensitive or allergic to beryllium. It is unclear what this sensitivity means. Studies have shown it to be an early sign of chronic beryllium disease (CBD) in many individuals. In others, sensitivity might simply mean that the person was exposed to beryllium and that his or her body has reacted. It might mean that an individual is more likely than others to get CBD. You are being offered the Be-LPT because doctors believe it is useful in detecting cases of CBD early or cases that might otherwise be missed or diagnosed as another type of lung problem. Once CBD is identified, doctors can determine the treatment needed to minimize the lung damage that CBD causes.

As in any other medical test, the Be-LPT sometimes fails or provides unclear results. The laboratory calls these results “uninterpretable.” Even when the test appears successful, it may appear positive when a person is not sensitive or allergic to beryllium. This is called a “false positive” result. It is also possible that the test will show “negative” results when a person is actually “sensitized” to beryllium. This is a “false negative” result. If you have an “uninterpretable” blood Be-LPT result, you will be asked to provide another blood sample so the test can be repeated. If you have “positive” results, you will be offered further medical tests to confirm or rule out CBD. Remember that you may refuse further tests at this point or at any point during your medical evaluations.

It is important for you to know that if the physical examination or the results from other tests suggest that you have CBD, you may be offered further medical tests. These medical tests may be offered even if your Be-LPT is “negative.”

Some individuals with confirmed “positive” Be-LPTs but no other signs of CBD have developed the disease. The likelihood of this happening will only be known after large groups of potentially exposed individuals have had their blood tested, have had further medical tests, and are studied for many years.

Do I have to have the Be-LPT done?

No. Your participation in the medical surveillance program is strictly voluntary. You may refuse any of the tests offered to you, including the Be-LPT. If you change your mind, you are

free to participate in the program at any time in the future. Talking with your family, your doctor, or other people you trust may help you decide. The physicians in the clinic that provide the tests can also help answer any questions that you might have.

What will happen if I decide to have the Be-LPT blood test?

A small amount of your blood will be drawn from a vein in your arm and sent to a laboratory. There is little physical risk in drawing blood. Slight pain and bruising may occur in a few individuals. Rarely, the needle puncture will become infected. Other routine medical evaluation tests may be offered when you have the Be-LPTs, including a physical examination, a chest X-ray, and breathing tests that help find signs of CBD, if they exist.

Other diseases may resemble CBD. Different medical tests can help a physician decide if a person has CBD or another disease. If the examining physician suspects that you have CBD, he or she will recommend additional medical tests to help confirm a diagnosis. Separate information regarding these additional medical tests will be given to you if they are recommended. Your consent will be requested when the extra tests are given. You can always refuse additional tests, if you so choose. Your employer will pay for all tests.

When will I receive the results of my Be-LPT blood test?

It could take 2 to 4 weeks for you to receive a letter informing you of your test results. The test itself usually takes 8 days to perform. The testing laboratory reports results to the physician who examined you, and he or she will notify you.

Could a positive Be-LPT blood test affect my job assignment?

Yes. If you have a positive Be-LPT or have been diagnosed with CBD, your employer may inform you that the SOMD has recommended that you be temporarily or permanently removed from working with beryllium. You will be given information and counseling to help you decide whether to accept medical removal. If you agree to medical removal, every effort will be made to offer you another job that you are qualified (or can be trained for in a short period) to perform and where the beryllium exposures will be as low as possible, but in no case above the action level.

If you are temporarily removed, you will maintain your total normal earnings, seniority, and other benefits until you are placed in another job or for 1 year, whichever comes first. If you are permanently removed, you will maintain your total normal earnings, seniority, and other benefits until you are placed in another job or for 2 years, whichever comes first. If you become physically unable to continue working, you may be eligible for workers' compensation and other benefits.

Will I lose any pay or any other benefits by having the examination during normal working hours?

No. Your examination will be scheduled during normal work hours. You will not be required to take leave to have the examination, nor will you lose pay or any other benefits.

What will happen to the records of the medical examination results?

The results of your Be-LPT and other screening tests will be made available to you and, with your consent, to your physician. The information also will become part of your medical record, which the clinic keeps.

The results of tests and examinations in your medical record will be available to the physicians and nurses in this clinic, and possibly to scientists conducting health studies. The test results in your medical records will be kept in specially secured files under the supervision of physicians and nurses in the clinic, separate from other personnel records. Your test results will be medically confidential data and will not be released to anyone other than those listed in the following, unless you provide written permission. The following groups will have direct access to this information:

1. Clinic staff members;
2. Medical specialists, who will provide or arrange for additional medical treatment or tests, if necessary;
3. U.S. Department of Energy Beryllium Registry staff; and
4. The Centers for Disease Control and Prevention and the National Institute for Occupational Safety and Health officials, who may require direct access to records that identify you by name for health studies.

If information about you is used in reports or a published health study, your identity will be disguised. You will not be identified in any published report or presentation.

What laws protect me if I consent to participate in the blood Be-LPT testing program?

State medical and nursing licensing boards enforce codes of ethics that require doctors and nurses to keep medical information confidential. The Privacy Act prevents unauthorized access to your DOE records without your permission. The information in records kept by your employer must be handled in accordance with the Americans with Disabilities Act and the Privacy Act of 1974. The consent form you sign also provides additional protection.

Can my privacy and the confidentiality of my medical records be guaranteed?

No. Access to or release of records could be required under court order or DOE directive, but it is unlikely. It would also be available as the Freedom of Information Act or Privacy Act provide, such as to Congress, to an individual upon a showing of compelling circumstances affecting the health and safety of an individual, etc. If you apply for another job or for insurance, you may be requested to release the records to a future employer or an insurance company. If, for medical reasons, it is recommended that you transfer to an area where you will not contact beryllium, and you elect to do so, the personnel department and your supervisor will be notified. They will not be told the specific results of your tests but, because of the restrictions, they may assume that your Be-LPT results were positive.

What is the DOE beryllium registry?

Your health and the health of all workers is a major concern to DOE. There is a need to learn more about CBD and what causes some individuals to react more strongly than others do. A DOE beryllium registry has been established to collect and maintain information on workers exposed to beryllium. This registry is a tool that will be used in health studies to better understand the nature of the disease. With it we can measure the burden of health effects related to beryllium exposure. The registry will also be used to evaluate the effectiveness of exposure control programs.

In addition to information about your beryllium-related exposures, the results of beryllium sensitization testing and/or CBD status collected by your employer will be added to the registry. Your employer must treat this information as confidential medical information and can only use or disclose this information in conformance with the Privacy Act of 1974, the Americans with Disabilities Act, and other applicable laws. Your employer will establish a unique identifier for you that will be included in the registry instead of your personal identifying information (such as your name and social security number). The unique identifier will be used to inform your employer of any study results that you and your employer's Site Occupational Medical Director (SOMD) should know about. The SOMD will know to whom the unique identifier refers and will notify you of these results. At no time will your name or other personal identifying information be included in any report. The confidentiality of personal information in DOE records is protected under the Privacy Act of 1974.