

What is the purpose of the National Supplemental Screening Program (NSSP)?

The purpose of this screening program is to determine whether U.S. Department of Energy (DOE) former workers may have developed an occupationally related illness as the result of their work at U.S. DOE facilities. As a former worker, you will be offered job-specific medical examinations. There will be no cost to you for the medical examinations. If you are found to possibly have an occupationally related illness, you will be referred to your private physician for follow-up and, if appropriate, to the Department of Labor (DOL) to determine your benefit eligibility or for further medical evaluation. Participation in the NSSP is completely voluntary. You may choose not to be in the program. If you agree to be in the program, you may withdraw from the program at any time. Your consent is indicated using the Informed Consent Form at the end of this Information Sheet.

Who is sponsoring this program?

DOE sponsors and funds this program through the Office of Environment, Health, Safety and Security (EHSS). Oak Ridge Associated Universities (ORAU) manages the program for DOE with its program partners: National Jewish Health (NJH); the Colorado School of Public Health's Center for Health, Work, & Environment at the University of Colorado; Acuity International; and Cority.

Who can receive a medical examination through the NSSP?

The NSSP can provide medical examinations to DOE former workers from any DOE covered facility regardless of where in the United States they are living.

Do I have to have the NSSP medical examination or do I have to have all of the tests performed that are offered under the NSSP?

No. Your participation in this medical screening program is strictly voluntary. You may refuse any of the tests offered to you. If you change your mind, you are free to participate further in the program at any time. Talking with your family, your doctor, or other people you trust may help you decide. The NSSP's medical professionals and staff can also help answer any questions that you might have and may be contacted at 1-866-812-6703.

What will happen if I decide to have the NSSP medical examination?

You will be scheduled by the NSSP team to have your medical examination, consisting of tests you agree to receive, performed in a medical facility. Depending on your specific exposures and the type of work you performed while working at a DOE facility, your NSSP medical examination may include the following:

- review of your work/exposure history
- physical examination
- height, weight, and vital measurements
- breathing test
- chest x-ray
- blood draw (for several types of blood tests including a test for beryllium sensitization)
- urine specimen collection
- test for blood in the stool (completed at your home and submitted by mail)
- hearing test

A blood specimen will be taken from a peripheral vein, usually in your arm. There is little physical risk in the blood draw procedure. In a few people, slight pain and a small area of bruising may occur at the site of the blood draw. The bruising usually subsides in 3-5 days.

When will I receive the results of my NSSP medical examination?

It takes on average 4 to 6 weeks for you to receive a letter from the NSSP physicians informing you of your medical examination results.

What happens if a medical abnormality is found during the medical examination?

A program physician will send you the results of the medical tests along with a recommendation that you provide all of this information to your personal physician for inclusion in your medical file and for any appropriate follow-up. The NSSP will NOT contact your physician directly except in an emergency or at your request. You should be aware that, as with most tests, the medical tests performed during the examination can yield results that are incorrect or unclear. It is important that you share the results of the NSSP examination with your personal physician as part of your continued health care.

If there is an abnormal result that could potentially impact your health before you are likely to receive your full exam results, you will receive a letter from an NSSP physician or nurse as soon as possible notifying you of the result(s). In some cases, depending on the level of urgency, you will also receive a phone call. The information contained in this urgent notification will also be contained in the final letter that you will receive once all of your NSSP exam results are available.

What are the costs and benefits to me if I participate in the program?

There is no financial cost to you for the screening examination. The program will pay for the medical examination and associated tests. Due to the short distance typically travelled for an NSSP examination, travel reimbursement is usually not necessary. However, reimbursement may be allowed for participants living in remote areas who must travel more than 150 miles one way to the nearest acceptable screening facility. All NSSP screening examination travel and lodging costs must be pre-authorized by an ORAU representative in order to receive reimbursement. Pre-authorization may be requested by calling the NSSP at 1-866-812-6703. The principal benefits to you of participation are the results of the medical examination. You also have the opportunity to contribute to our understanding of health as it may relate to exposures associated with work at DOE facilities.

The program will not pay for any follow-up medical care. You may elect to follow or disregard any recommendation or referral made by the program physicians.

The NSSP staff will make sure you have the information you need if you wish to apply for benefits under the Department of Labor's Energy Employees Occupational Illness Compensation Program Act of 2000 (DOL EEOICPA). Only the DOL, not the DOE or the NSSP, may determine whether a worker meets the qualifications for benefits.

In the event of injury directly resulting from your participation in this program, you should contact the NSSP at 1-866-812-6703. Neither the NSSP nor the Federal government will be able to provide you with medical treatment, either long-term or short-term, or financial compensation except as may be provided through whatever remedies are normally available by law. The project's Senior Director and Principal Investigator, Dr. Jamie Stalker, will be responsible for reporting any adverse events to DOE and to the Central DOE Institutional Review Board.

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

Your test results will be treated as confidential medical records and used or disclosed only as provided by the Privacy Act of 1974, the Americans with Disabilities Act (ADA), or as required by a court order or other law. The results of aggregated NSSP tests and examinations may be published in technical reports or presented at scientific meetings but will not identify any individuals. The results of your medical examination and other screening tests will be made available to you and, if requested by you, to your personal physician.

This voluntary medical screening program will provide a medical examination at no cost to you. Identifiable information about you and your test results will be placed in a secure database that will be used by the medical surveillance team to notify you of results and keep track of where you are in the medical screening process. It is possible that at some time in the future, other researchers who are studying occupationally related illnesses in the DOE workforce may request access to the information contained in this database. The information will not be given to any researchers unless their proposed use of the information is reviewed and approved by an Institutional Review Board (IRB), which is required by law to review research proposals involving humans as participants to ensure protection of their rights and welfare. Prior to information being released, an IRB review will be performed concerning the scientific merit of the research and the methods proposed to ensure that the human participation is justified and ethical.

The results of your medical examination may be available to the people listed below. Some of these people may require access to records that identify you by name:

1. The ORAU NSSP staff, who will review your results and maintain permanent files for your records.
2. Physicians from ORAU, National Jewish Health (NJH), and the Colorado School of Public Health's Center for Health, Work, & Environment at the University of Colorado, who will review your results and explain whether further testing is necessary for you.
3. Data specialists from Cority, who will maintain the computer records system for the NSSP.
4. Medical support staff at Acuity International, who will make your appointment for your examination and send you information before your appointment.
5. Others as required by the ADA, the Privacy Act of 1974, or by court order or other law.

What laws protect my privacy if I consent to participate in the NSSP?

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 records without your permission. The information in the records must be handled in accordance with rules established by the ADA and the Privacy Act of 1974. The consent form you sign provides additional protection.

Can privacy and confidentiality of my medical records be guaranteed?

No. Access to or release of records could be required under court order, but this is unlikely. Records could also be made available as provided by the Freedom of Information Act or the Privacy Act under conditions such as an emergence of compelling circumstances potentially affecting the health and safety of an individual, for example. If you apply for another job or for insurance, you may be asked to release the records to that future employer or insurance company. Personal identifiers will not be published in any reports.

NATIONAL SUPPLEMENTAL SCREENING PROGRAM (NSSP) INFORMED CONSENT STATEMENT

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Sponsor: Department of Energy/Office of Environment, Health, Safety, and Security

PARTICIPANT'S AUTHORIZATION

I have read: (Please initial items to indicate that you have read them.)

- _____ the attached information about the NSSP. I have or will contact the NSSP at 1-866-812-6703 to discuss any questions that I may have prior to or after my scheduled appointment. I am free to withdraw without penalty or loss of benefits at any time from the program for which I am volunteering. I may request at any time to have my personal information and data removed from all NSSP databases. I will receive the results of any medical tests from the NSSP physicians who are directing and reviewing the medical examination.
- _____ that medical follow up is not provided by this program. I may pursue or disregard any recommendations or referrals made by the Program physicians.
- _____ that the results of any tests, examinations, or analyses of this medical screening program may be published or presented at meetings, but that I will not be identified personally.
- _____ that the records of my participation in this program and the results of any tests or examinations to which I consent are confidential medical records that may be used or disclosed only as provided by the Americans with Disabilities Act, the Privacy Act of 1974, or as required by a court order or other law.
- _____ that if I have additional questions about this program or my participation in it, I can contact Dr. Jamie Stalker (ORAU) at (303) 423-9585, or the Chair of the Central Department of Energy Institutional Review Board at (865) 574-4359.
- _____ that I will be given a copy of this Informed Consent Form with the results of my NSSP examination.

(continued on the following page)

CONSENT STATEMENT

The purpose of the NSSP, procedures to be followed, risks, and benefits have been explained to me. **Any questions I may have concerning any part of the physical examination and/or medical results should be directed to the NSSP at 1-866-812-6703.** I have read this consent form and agree to be in this program. I may withdraw at any time, and I will be given a signed copy of this consent form with the results of my examination.

Participant Name

SSN

Participant Signature

Date

The Department of Energy may develop new medical screening and/or research studies in the future. Would you like to have your name and address forwarded to DOE so that they can notify you about new programs? [Neither your SSN nor any medical information will be transferred; only your name and address.]

Yes. I consent to have my contact information forwarded to DOE.

No. I do not consent to have my contact information shared with DOE.