Living With Asbestos-Related Illness

A Self-Care Guide

ATSDR
AGENCY FOR TOXIC SUBSTANCES
AND DISEASE REGISTRY

What Is Asbestos?

Asbestos is a rare, naturally occurring mineral with a chainlike crystal structure. Asbestos deposits can be found throughout the world. Deposits are still mined in Australia, Canada, South Africa, and the former Soviet Union. Asbestos is usually found mixed into other minerals. Asbestos is dangerous only if its broken crystal fibers float in the air after being disturbed.

Over the years, asbestos has had many uses. Pipe insulation, automotive brakes, shingles, wall-board, and blown-in insulation are just a few of the products that once contained asbestos. Although the federal government suspended production of most asbestos products in the early 1970s, instal-lation of these products continued through the late 1970s and even into the early 1980s. Asbestos fibers can be released during renovations of older buildings.

Nearly everyone is exposed to asbestos at some time in their lives because asbestos fibers have been frequently used in modern industry and they are also found in nature. The fibers float freely. These lightweight fibers can remain in the air for long periods of time.

The risk of developing asbestos-related illness varies with the type of industry in which the exposure occurred and with the extent of exposure.

Generally, asbestos fibers are long, thin, tough, and so small that they cannot be seen. There are two types of asbestos, one is serpentine, which looks like a corkscrew and the other is amphiboles which have long, needle-like fibers. When the fibers float in the air, they are easily inhaled. In most cases the fibers must be breathed in high concentrations over a long period of time to be considered a concern for a person's health.

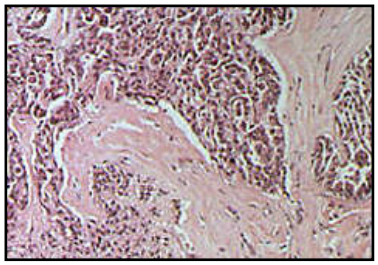
Scanning electron micrograph of asbestiform amphibole

Asbestos fibers can easily enter the lungs and become trapped in the lung tissues because they are so small. When these fibers are inhaled, they can penetrate and irritate the lungs. White blood cells attack the fiber, and eventually the site becomes scarred. Asbestos fibers break down extremely slowly over time. The fibers can remain in the body for many years and build up in the lungs. Because they attach to the lining of the lungs and airways, the fibers cannot be coughed out or washed out of the lung tissue. The area around the fiber becomes inflamed and, eventually, scarred. As a person's exposure to fibers increases by breathing more fibers, that person's risk of disease also increases. Diseases related to exposure to asbestos do not appear for several years, possibly 15 to 40 years after exposure.

Individuals who have been exposed (or suspect they have been exposed) to asbestos dust on the job or at home via a family contact should inform their physician of their exposure history and any symptoms. A thorough physical exam, including a chest x-ray and lung function tests, may be recommended. Interpretation of the chest x-ray may require the help of a specialist who is experienced in reading x-rays for asbestos-related illness. Other tests may be necessary.

Asbestos-Related Illnesses

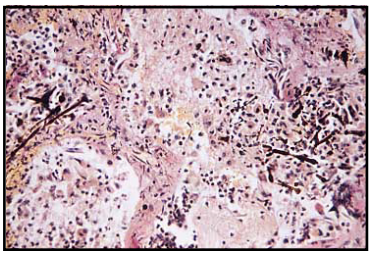
Lung cancer is a malignant tumor that invades and obstructs the lung's air passages. Cigarette smoking greatly increases the likelihood of a person developing lung cancer as the result of asbestos exposure. The most common symptoms of lung cancer are coughing, wheezing and labored breathing. Other symptoms of lung cancer include shortness of breath, persistent chest pain, hoarseness, and anemia as well as weight loss, fever, chills and night sweats. People who develop these symptoms do not necessarily have lung cancer, but they should consult a physician for advice.



Microscopic view of mesothelioma cells.

Mesothelioma is a very rare cancer of the lining of the chest or abdomen. Most mesotheliomas are caused by exposure to asbestos. By the time they are diagnosed, mesotheliomas are almost always fatal.

Asbestosis is a serious, progressive, long-term disease of the lungs that can get worse as time passes. Asbestosis is not a cancer. It is a disease that restricts how the lungs work, which makes it hard to breathe. Asbestosis is caused by inhaling asbestos fibers that irritate and inflame tissues, which creates scar tissue in the lungs. Along with scarring of the lung tissues, scarring can occur along the lining of the chest wall called the pleura. The scarring makes it hard to breathe and difficult for oxygen and carbon dioxide to pass through the lungs.



Microscopic view of lung tissue with asbestosis.

Signs and Symptoms of asbestosis include

- shortness of breath is the primary symptom
- a persistent and productive cough (a cough that expels mucus)
- chest tightness
- chest pain
- loss of appetite
- a dry, crackling sound in the lungs while inhaling.

Asbestosis generally progresses slowly, but the rate of progress can vary greatly from one asbestos exposed person to another. The advancement of symptoms may occur even without additional exposure. It may even speed up with continued exposure. Rapid progression after the first symptoms appear is not common, but it can occur in some people. It can become increasingly difficult to breath as the symptoms progress over time. Lung tissues and the lining of the chest wall can thicken and harden from the thinness and stretchiness of a ballon to that of an orange peel.

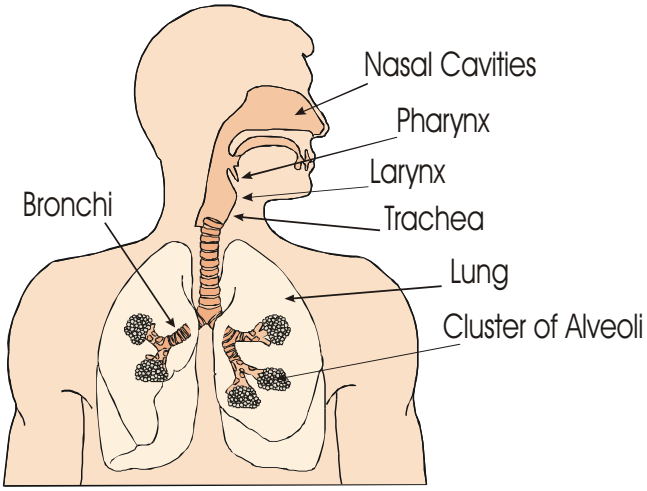
As the disease progresses, the individual's shortness of breath becomes more pronounced. The shortness of breath is usually noted first during heavy work or exercise. It will eventually interfere with the ability to carry out everyday activities and the individual may require oxygen. The end result of progression is failure of the lungs and eventual heart failure due to the stress being placed on the heart.

The Respiratory System

The body needs oxygen to grow and function. The respiratory system supplies oxygen to the individual tissue cells and removes carbon dioxide from the blood.

The respiratory system is an arrangement of spaces and passageways that bring air into the lungs. These spaces include the nasal cavities; the pharynx, which is used by both the digestive tract and the respiratory system; the voice box or larynx; the trachea or windpipe; and the lungs, which include the bronchial tubes and alveoli (or air sacs).

Nasal Cavities. It is better to breathe through the nose than the mouth because (a) foreign bodies such as dust particles are filtered out by the hairs of the nostrils or caught in the surface mucus, (b) air is warmed by the blood in the vascular membrane, and (c) air is moistened by the mucus in the nasal passage.

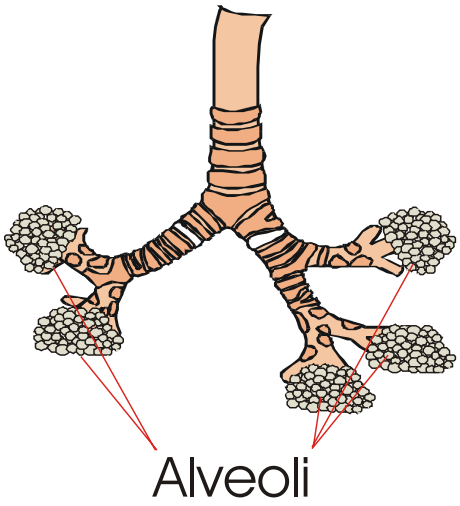


Pharynx. The muscular pharynx or throat carries air into the respiratory tract and also carries foods and liquids into the digestive tract.

Larynx. The larynx, or voice box, is between the pharynx and the trachea. The larynx is lined with little hairs attached to the mucous membranes. The hairs (cilia) trap dust and other particles and move them upward to the pharynx to be expelled by coughing, sneezing, or nose blowing. The cilia are the primary defense of the immune system in the respiratory tract.

Trachea. The trachea, or windpipe, is a tube that extends from the lower edge of the larynx to the upper part of the chest above the heart. The trachea has a framework of cartilage to keep it open. The trachea moves air between the larynx and the lungs.

Bronchi and Bronchioles. The trachea divides into two branches (bronchi), which enter the lungs. The right bronchus is considerably larger than the left and extends downward in a more vertical direction. Each bronchus enters the lung and immediately subdivides again and again, forming smaller divisions. The smallest of the divisions are called the bronchioles.



Alveoli. At the end of the smallest subdivisions of the bronchioles are clusters of air sacs that look like a bunch of tiny grapes. The sacs are called the alveoli. The average adult lung contains about 600 million alveoli. The exchange of oxygen and carbon dioxide in the blood takes place in the alveoli.

Oxygen-rich blood is sent to the heart, which pumps it through the body. The red blood cells carry carbon dioxide to the alveoli, and then the carbon dioxide leaves the body through exhaled breath.

Breathing that is too shallow, slow, or the result of reduced lung function is called hypoventilation. Hypoventilation results in inadequate oxygenation of the blood. Respiratory obstruction, lung disease, or exposure to toxicants can also cause this condition.

Amazing Facts About the Lungs

- The right lung is slightly larger than the left.
- Hairs in the nose help clean and warm the air we breathe.
- The surface area of the lungs is roughly the same size as a tennis court.
- The capillaries in the lungs would extend 994 miles (1,600 kilometers) if placed end to end.
- The highest record "sneeze speed" is 102.5 miles (165 kilometers) per hour.

Asbestos fibers enter the body from the air we breathe. Most of the small particles we breathe—like dust and pollen—are stopped or trapped by the mucous lining and nasal hairs before entering the small airways of the lungs. Because asbestos fibers are so small and thin, they pass all the way down to the small airways and alveoli (or air sacs), where the oxygen-carbon dioxide gas exchange occurs.

The immune system, the body's defense system, considers asbestos fibers foreign invaders and tries to break them down and remove them from the lung.

Breakdown Process

Each alveolus has many cleaning cells, called macrophages, that destroy foreign invaders in the alveoli. Because asbestos fibers are too long and sharp, macrophages cannot destroy them. Macrophages then try to surround the fiber so that it cannot cause damage. In doing so, the macrophage is essentially cut open and its digestive molecules are spilled on the alveoli. This causes scar tissue to form in the spaces around the small airways and alveoli.

Scarring and thickening of the lung tissue decreases the ability of the lungs to exchange oxygen and carbon dioxide between the alveoli and the blood cells, so breathing becomes more difficult.

Treatment of Asbestos Related Illness

Unfortunately, no cure exists for asbestosis. Treatment involves preventing further complications of the disease and treating its symptoms. For information about cancer treatment, contact the National Cancer Institute's Cancer Information Service, whose toll free number is 1-800-4-CANCER.

Respiratory Infections

People with chronic lung diseases such as asbestosis are more susceptible to respiratory infections because the lungs are already damaged. One of the most important preventative measures is to produce a productive cough, or a cough that brings up mucus.

It is important to cough effectively to clear out the air passages. An effective cough is moist and brings mucus up from the lungs and air passageways. An ineffective cough reduces airflow and causes respiratory muscle fatigue. If mucus and other foreign bodies remain in the respiratory tract, they can pool in the airways, making it difficult to expel bacteria and increasing the risk of infection.

Your doctor will probably recommend a humidifier, breathing therapies, and chest percussion to ensure a productive cough. Very dry air increases shortness of breath and thickens the mucus in your lungs. These steps loosen and thin out bronchial secretions, allowing them to be expelled by the cough.

Make an effort to prevent infection. People with asbestosis should receive aggressive medical care, including frequent use of antibiotics when warranted, for any respiratory infection.

Take Care of Yourself To Prevent Infection

Keep a diary of when you have trouble breathing. Note how often you have trouble, how bad it is, and what you were doing before you had trouble. The diary will help you recognize and avoid events that trigger breathing trouble.

Stay inside, if possible, when air pollution and pollen counts are high. An air-filtering machine can improve the indoor air quality in your home.

Avoid breathing pollutants that can aggravate shortness of breath. Such pollutants include fumes from heavy traffic, smog, aerosol sprays, and products that produce chemical vapors (for example, paint, kerosene, and cleaning agents).

In cold weather, **breathe through your nose** and cover your mouth and nose with a scarf.

Exercise is important to increase the strength and endurance of the respiratory muscles. Increased physical activity increases respiratory muscle strength.

Drink lots of fluids—at least six glasses of water daily, unless your doctor tells you differently.

Eat healthy foods including lots of fruits and vegetables. Poor eating habits result in smaller muscle mass and are an enemy of the patient with respiratory disease.

Take measures to correct an anemic condition and/or electrolyte imbalance in your blood. Such measures could improve cardiopulmonary performance.

Watch your salt intake. Keep it low.

Breathe slowly.

To lower your risk of colds or flu, **wash your hands often**.

Get flu and pneumonia vaccinations every year (between September and December). Caregivers and all household members, whether or not they provide care, also should be vaccinated.

Avoid situations that might expose you to respiratory infections (for example, large crowds).

Follow your doctor's instructions on taking your medicines, oxygen therapy, and/or chest physiotherapy.

Sleep 7 or 8 hours every night.

Take several short rests during the day. Learn to conserve your energy and avoid getting too tired.

Take special precautions with your personal hygiene. Wash your hands before taking your medication or handling your oxygen equipment.

Do not try to treat yourself. Over-the-counter cold remedies might worsen the problem, so do not use them unless your doctor tells you it is okay.

- **Have regular chest x-rays** to screen for cancers associated with asbestos exposure.

- **Call your doctor** if any of the following signs occur:
  - Fever
  - Increased coughing, wheezing, or breathing
  - Changes in mucus (mucus is thicker; either more or less mucus is present than usual; mucus has a foul odor; or mucus is green, yellow, brown, pink, or red)
  - Stuffy nose, sneezing, or sore throat
  - Increased fatigue or weakness
  - Weight gain or loss of more than 6 pounds within a week
  - Swollen ankles or feet.

Symptoms of respiratory infections can appear suddenly and worsen quickly. When an infection develops, it is important to start treatment right away. Your doctor might prescribe antibiotics or other drugs to get the infection under control before it becomes serious. See your doctor as soon as you feel sick.

Self-Care

No cure exists for asbestosis, but taking care of yourself can help you maintain a more comfortable life. Some self-care tips and techniques follow.

- **Stay away from smoke and smokers.** If you smoke, now would be a good time to quit. Smoking can increase the rate of disease progression, and it also increases the risk of lung cancer. Even if you have been smoking for years—or you already have lung disease—quitting smoking now will greatly improve your health. The tracheal cilia will begin working again and help keep your lungs swept clean. The blood vessels will relax, allowing the blood to flow normally, so your heart will no longer have to work as hard. The lung tissue will become healthier and you will breathe easier.

  A structured program has a good chance of successfully helping smokers quit the habit. Recent trials using the nicotine patch and antidepressants have been shown to be more effective than counseling in helping smokers quit.

- **Participate in respiratory therapies (such as bronchial drainage) as recommended by your doctor.** Your doctor might recommend using an ultrasonic mist humidifier that assists in clearing secretions from the lungs. Respiratory treatments that remove secretions from the lung through postural drainage might also be used.

- Proper training and adherence to **decontamination techniques** can minimize the risk of infection associated with respiratory therapy devices.

  - Clean all reusable respiratory therapy equipment such as ventilator circuitry, nebulizers, aerosol tubing, and peak flow meters twice weekly. Consult your provider about cleansing routines for respiratory equipment.

- All cleaned devices must be allowed to air dry thoroughly before reassembling for use. Moisture trapped in the devices can be a potential reservoir for bacteria, viruses and fungi

- All ventilator filters should be cleaned and changed as often as the manufacturer recommends.

Oxygen. If your doctor has prescribed oxygen, you will have a liquid oxygen unit, an oxygen tank, or an oxygen concentrator. You will breathe the oxygen through either a mask or nasal cannulae (two short prongs that fit just inside your nostrils). The system will also have a humidifier to warm and moisten the oxygen.

It is a good idea to also have a small portable oxygen tank available in case of power failure.

Only your doctor can determine how much oxygen you need. You should never change the flow rate without instructions from your doctor. The medical supply company will show you how to set the flow rate and how to care for the equipment. Keep the supplier's telephone number handy so you can call if the system does not work properly.

Sometimes it is hard to tell whether oxygen is flowing through the tubes. If you have doubts, check to be sure that the system is turned on and the tubing does not have any kinks. If you still are not sure, place the nasal cannulae in a glass of water with the prongs up and watch for bubbles. If no bubbles appear, oxygen is not flowing through the tubes and you need to call your supplier.

Oxygen is very combustible. Be sure to keep your oxygen unit away from open flames and heat, including lit cigarettes, gas stoves, space heaters, or kerosene heaters.

When traveling around town, be sure to plan for an adequate supply of oxygen and know how much time you can safely travel between refills. Always allow for a 20%–25% safety margin to cover any unexpected delays. When traveling, keep the oxygen container upright and secure at all times.

Traveling With Oxygen

- Discuss your travel plans with your doctor to be sure it is all right for you to travel and to find out how long your trip can be.

- Contact your oxygen supply company about your travel plans. The company will recommend the equipment you need and help determine the time you can safely travel between refills. Get the oxygen equipment with which you will travel ahead of time so you can become familiar with how to operate it. Your supplier can also arrange to have oxygen supplied to you at your destination.

- Check with your insurance company. You may have to pay in advance for equipment and submit the insurance claims after you return home. Be sure to keep your receipts.

- Always keep your prescription with you throughout the trip.

Traveling by Bus

Bus lines do permit travel with oxygen equipment. However, to prevent any unexpected problems, check in advance. Most bus companies permit you to take one E cylinder onto the bus, but extra tanks are not allowed in the baggage compartment. You must be able to put your tank on and take it off by yourself.

Traveling by Train
Make reservations with Amtrak at least 4 days in advance, even for short trips. You may bring two cylinders, either size E or F, and the oxygen unit must be self-contained and not on wheels. On overnight trips, you must have a sleeper compartment, where you are required to stay while using oxygen. Meals can be sent to your sleeper.

Traveling by Ship
Cruise line regulations differ and are subject to change, so you must contact the cruise line regarding current rules. Some cruise lines permit you to travel only with oxygen cylinders and limit the number you may bring on board. Be prepared to supply the following information from your doctor: a prescription stating the quantity of oxygen and the flow rate, a letter describing your diagnosis, and a statement that you are approved for travel.

Traveling by Plane
Regulations vary from one airline to another and are subject to change. Always call ahead of time to inquire about current rules. Some airlines will not permit passengers to use oxygen. Others airlines are willing to provide oxygen if you make advance arrangements, but you must use their oxygen supply. Airlines do not allow passengers to bring oxygen on board the plane. Always bring your own nasal prongs: some airlines use only simple oxygen masks, which allow carbon dioxide buildup. Also bring a nipple adapter that fits all tubing.

You must make reservations 2 to 5 days in advance, depending on the individual airline's rules. Be sure to ask what documents you will need to supply. Airline documentation requirements are similar to those of cruise lines, and some airlines also have special forms that must be filled out by your doctor. You might have to sign a liability statement. In a few cases, you are required to bring a companion with you on the flight. Additional charges vary, but expect to pay about $50 extra.

Allow at least 1 hour between connecting flights. Remember that you must arrange for oxygen for the time between flights. Local oxygen suppliers will provide this service for layovers between flights. Whenever possible, use small airports because they usually have fewer delays and their boarding gates are closer together.

Lodging
Hotels and motels are usually very accommodating about special needs. Someone is usually available to transport your oxygen tank. Contact your local supply company about arranging for a supply company at your destination to set up the equipment in the room before you arrive.

Relaxation and Breathing Techniques

The feeling of not being able to get enough air into your lungs is frightening. Breathing training is aimed at controlling the respiratory rate and breathing pattern, thus decreasing the risk that used air will not stay in your lungs. Breathing training also attempts to improve the position and function of the respiratory muscles and effectiveness of coughs.

You can do exercises to help you breathe more easily. Practice the exercises daily so that when you are having problems with shortness of breath, you will do them naturally and not panic.

- **Pursed-Lip Breathing**: Pursed-lip breathing will slow down your breathing so that it is more efficient (breathing fast only worsens shortness of breath). Pursed- lip breathing can be done anywhere.
    1. Breathe in slowly through your nose. Hold your breath for 3 seconds.
    2. Purse your lips as if you are going to whistle.
    3. Breathe out slowly through your pursed lips for 6 seconds.

- **Abdominal/Diaphragm Breathing**: Abdominal breathing also slows down your breathing and helps relax your entire body.
    1. Lie on your back in a comfortable position with a pillow under your head and knees.
    2. Rest one hand on your abdomen just below your rib cage. Rest the other hand your chest.
    3. Slowly breathe in and out through your nose using your abdominal muscles. The hand resting on your abdomen will rise when you breathe in and fall when you breathe out. The hand on your chest should be almost still. Repeat three or four times before resting.

- **Active Cycle of Breathing Technique (ACBT)**: ACBT should be discussed with your doctor before implementation. ACBT is a series of breathing techniques that help clear secretions and improve aeration (the delivery of air to the alveoli [air sacs]). ACBT can be done sitting upright. This technique combines breathing exercises with the huff cough and has three components in a set cycle. The cycle is repeated until the huff becomes dry or nonproductive, or when 20 minutes have passed. Ask your doctor for instructions on this therapy

Pulmonary Rehabilitation

Patients with advanced lung disease may have emotional disorders, mainly depression and anxiety. In addition to appropriate medical therapy for theses disorders, exercise such as a pulmonary rehabilitation program can help lessen these feelings.

Talk to your doctor about participating in a pulmonary rehabilitation program. Pulmonary rehabilitation uses different therapeutic components for persons with pulmonary disease. The goal of pulmonary rehabilitation is achieving and maintaining the patient's maximum level of independence and functional ability in the community.
Pulmonary rehabilitation is becoming a crucial component of the overall therapy of many patients. It offers the best treatment option for patients with chronic respiratory illnesses. Pulmonary rehabilitation has helped people achieve increased exercise capacity and endurance; improved health-related quality of life; decreased shortness of breath; and fewer hospital admissions, even among patients with the most severe degree of lung disease.

The goals of a pulmonary rehabilitation program are to

- Reduce work of breathing
- Improve pulmonary function
- Alleviate shortness of breath
- Increase efficiency of energy use
- Correct nutrition deficiencies
- Improve exercise performance and daily activities
- Restore a positive outlook
- Improve emotional state
- Decrease health-related costs
- Improve survival.

If you are interested in pulmonary rehabilitation, ask your doctor to help you design a program that will work for you.

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This guide provides the patient living with asbestos-related illnesses and his or her family with skills and information to help them adapt and cope with their illness.

Use of trade names and commercial sources is for identification and does not imply endorsement by the Agency for Toxic Substances and Disease Registry or the U.S. Department of Health and Human Services.

For more information, contact ATSDR's toll-free information line:

(888) 42-ATSDR. . . that's (888) 422-8737

ATSDR's Internet address is www.atsdr.cdc.gov

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Appendix C. List of Regional Physicians Certified in Pulmonary Disease

A community member requested ATSDR to provide a list of board-certified pulmonologists in the Libby area. ATSDR performed a search on the American Board of Medical Specialties' (ABMS') database at www.abms.org. to locate physicians in Montana, Idaho, and Washington who were board-certified in the subspecialty pulmonary disease. Listed below are those certified physicians whose address at the time of the search was within 350 miles of Libby, Montana. This information is provided with the permission of ABMS solely for the convenience of the Libby community. ATSDR does not endorse any individual physician listed and will not pay for any services provided by the listed physicians.

The search was performed on October 25, 2002. Due to the possibility of reporting and processing delays, and because the list might have been updated since the search, the accuracy and completeness of the information cannot be guaranteed. Neither ATSDR nor ABMS can be held responsible for incomplete or inaccurate information. Physician certification information in the ABMS database is updated periodically with data provided by its member boards. For updated information, consumers can register to perform searches on the ABMS Web site, or they can verify the certification of a physician by calling 1-866-ASK-ABMS.

Name	City	State
William Bernard Bekemeyer Jr	Missoula	Montana
Richard Dyer Blevins	Great Falls	Montana
Ryland P. Byrd	Butte	Montana
Thomas Shull Lemire	Missoula	Montana
C. Paul Loehnen	Missoula	Montana
Brent Parker Pistorese	Kalispell	Montana
Keith Janes Popovich	Butte	Montana
Sripathi Ramakrishna	Helena	Montana
Henry Dominic Covelli	Coeur D'Alene	Idaho
Hugh Franscisco Haegelin	Lewiston	Idaho
Luke Anthony Pluto	Lewiston	Idaho
Paul Albert Allen	Richland	Washington
Scot Llewellyn Bradley	Spokane	Washington
Timothy Edward Bruya	Spokane	Washington
Richard B. Byrd	Spokane	Washington
Timothy Michael Chestnut	Spokane	Washington
Richard Wayne Felt	Walla Walla	Washington
Todd Robert Green	Spokane	Washington
Samuel Greg Joseph	Spokane	Washington
William Scott Klipper	Kennewick	Washington
Lawrence Edward Klock	Spokane	Washington
Richard James Lambert	Spokane	Washington
Robert Edward Moss	Spokane	Washington
John Naylor	Spokane	Washington
Robert Paul Stevens	Wenatchee	Washington
Donald Duncan Storey	Spokane	Washington
Gladson M. Vaz	Pasco	Washington
Alan Coombs Whitehouse	Spokane	Washington