What Is Paget's Disease of Bone?

Fast Facts: An Easy-to-Read Series of Publications for the Public

Paget's disease causes bones to grow too large and weak. You can have Paget's disease in any bones in your body, but most people have it in their spine, pelvis, skull, or leg bones. The disease may affect only one bone or several bones, but it does not affect the entire skeleton. Bones with Paget's disease may break more easily, and the disease can lead to other health problems.

Who Gets Paget's Disease?

About one million people in the United States have Paget's disease. The disease is more common in older people and those of Northern European descent. Men are more likely than women to have the disease.

What Causes Paget's Disease?

Doctors are not sure what causes Paget's disease. They think that a virus may cause it in some cases. It also tends to run in families. Your doctor might suggest that your brothers, sisters, and children have blood tests every 2 or 3 years starting at the age of 40 to check for the disease.

What Are the Symptoms of Paget's Disease?

Many people do not know they have Paget's disease because they have only mild symptoms. For others, signs and symptoms can include:

- Pain
- Enlarged bones
- Broken bones
- Damaged cartilage in joints.

If you have Paget's disease in your leg bones, you may also have bowed legs. Your spine might curve if the disease is in the bones of the spine.

People with Paget's disease in the bones of the skull sometimes have:

- Headaches
- Hearing loss
- Large head size

Symptoms get worse slowly, and the disease does not spread to other bones.
What Is Paget’s Disease of Bone?

Fast Facts: An Easy-to-Read Series of Publications for the Public

How Is Paget's Disease Diagnosed?
Most often, Paget's disease is diagnosed with x rays. Your doctor may also order:

- An alkaline phosphatase blood test. People with Paget's disease have too much of this enzyme in their blood.
- A bone scan. A bone scan can show which bones the disease has affected.

Early diagnosis and treatment can prevent some symptoms from getting worse.

What Other Medical Problems Might Occur?
Paget's disease may lead to other medical problems, such as:

- Arthritis. The long bones in your leg may bow and press on nearby joints. Enlarged bone may cause more wear and tear on joints. In these cases, joint pain may be due to both Paget's disease and arthritis.
- Hearing loss. If you have Paget's disease in your skull or the bone surrounding your inner ear, you may lose some hearing. Treatment may slow or stop the hearing loss. Hearing aids may also help.
- Heart disease. In severe Paget's disease, the heart has to work harder to pump blood to affected bones.
- Kidney stones. Kidney stones are more common in people with Paget's disease.
- Nervous system problems. Bone with Paget's disease can press on the brain, spinal cord, or nerves. This can slow blood flow to the brain and spinal cord and cause pain.
- Bone cancer. Rarely, people with Paget's disease get cancer of the bone. This can cause sudden or increased bone pain.
- Loose teeth. If you have the disease in bones of your face, your teeth may become loose. This makes it hard to chew food.
- Vision loss. Rarely, people with Paget's disease in the skull may lose some vision.

Who Treats Paget's Disease?
Paget's disease can affect many parts of the body. You may need to see one or more types of doctors, such as:

- Endocrinologists (doctors who treat metabolic bone diseases like Paget's disease).
- Rheumatologists (doctors who treat arthritis and other joint problems).
- Orthopaedic surgeons (doctors who treat bone problems).
- Neurologists (doctors who treat brain and nerve problems).
- Otolaryngologists (doctors who treat ear, nose, and throat problems).
How Is Paget's Disease Treated?

Paget's disease is treated with medicine and sometimes surgery. A good diet and exercise are also important.

**Medicine**

Two main types of medicines are approved to treat Paget's disease.

- **Bisphosphonates.** These medicines help relieve pain and keep the disease from getting worse.
- **Calcitonin.** This is a hormone made by the thyroid gland. It may be used for certain patients but it does not work as well as bisphosphonates and is not used as often.

**Surgery**

Surgery is sometimes needed to treat broken bones, malformed bones, or severe arthritis.

- **Broken bones.** Surgery may be needed to set a broken bone.
- **Malformed bones.** Surgery to straighten bones may reduce the pain in joints such as the knee.
- **Severe arthritis.** People with severe arthritis are treated with medicine and physical therapy. If these do not work well, a hip or knee may need to be replaced.

**Diet**

People with Paget's disease do not need a special diet. But, to maintain strong bones, you should get 1,200 mg of calcium and at least 400 IU of vitamin D every day. After age 70, you should take 600 IU of vitamin D each day. If you have had kidney stones, talk with your doctor about how much calcium and vitamin D to take.

**Exercise**

Exercise helps build strong bones, prevents weight gain, and keeps joints mobile. Before starting a new exercise plan, talk with your doctor.

**For More Information About Paget's Disease of Bone and Other Related Conditions:**

NIH Osteoporosis and Related Bone Diseases ~ National Resource Center
2 AMS Circle
Bethesda, MD 20892–3676
Phone: 202–223–0344
Toll free: 800–624–BONE (624–2663)
TTY: 202–466–4315
Fax: 202–293–2356
Email: NIAMSBoneInfo@mail.nih.gov
Website: www.bones.nih.gov

The information in this publication was summarized in easy-to-read format from a more detailed publication. To order the Paget's Disease of Bone Q&A full-text version, please contact the NIAMS using the contact information above.

The NIH Osteoporosis and Related Bone Diseases ~ National Resource Center acknowledges the assistance of The Paget Foundation (www.paget.org) in the preparation of this publication.
For Your Information

This publication may contain information about medications used to treat the health condition discussed here. When this publication was printed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration (FDA) toll free at 888–INFO–FDA (888–463–6332) or visit its website at www.fda.gov. For additional information on specific medications, visit Drugs@FDA at www.accessdata.fda.gov/scripts/cder/drugsatfda. Drugs@FDA is a searchable catalog of FDA-approved drug products.