



# Facts a New Patient Needs to Know About Paget's Disease of Bone

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The NIH Osteoporosis and Related Bone Diseases ~ National Resource Center is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases with contributions from the National Institute of Child Health and Human Development, National Institute of Dental and Craniofacial Research, National Institute of Diabetes and Digestive and Kidney Diseases, NIH Office of Research on Women's Health, DHHS Office on Women's Health, and the National Institute on Aging.

*The National Institutes of Health (NIH) is a component of the U.S. Department of Health and Human Services.*



## What Is Paget's Disease of Bone?

Paget's disease of bone causes bones to grow larger and weaker than normal. The disease may affect one or more bones but does not spread from affected bones to other bones in the body. You can have Paget's disease in any bone in your body, but most people have it in their pelvis, skull, spine, or leg bones. These bones may become misshapen, and they can break more easily because they are weaker than normal bones. Some people with Paget's disease feel pain in these bones, too.

## I've Never Heard of Paget's Disease Before. How Common Is It?

An estimated 1 million people in the U.S. have Paget's disease, or about 1.3 people per 100 men and women age 45-74. The disease is more common in older people and those of Northern European heritage. Men are about twice as likely as women to have the disease.

## Is Paget's Disease of Bone a Form of Arthritis?

People with Paget's disease often have arthritis at the same time, but they are different diseases. Sometimes Paget's disease is confused with arthritis because the pain from Paget's disease may be located on the part of the bone closest to a joint. So, it may feel a lot like the joint pain of arthritis. Paget's disease can cause arthritis over time when enlarged and misshapen bones put extra stress on nearby joints. Your doctor may use several tests to help tell if you have Paget's disease or not.

## How Did I Get Paget's Disease?

Doctors are not sure what causes the disease. Some people have hereditary Paget's disease, which means it runs in their family and was passed down by their parents. But most people do not have any relatives with Paget's disease. Doctors think a virus also may be the cause of Paget's disease in some cases. They are studying different kinds of viruses to try to find ones that may cause the disease.

## Will My Paget's Disease Get Worse? What Should I Expect?

Paget's disease does not affect everyone in the same way. Some people have a very mild case with few or no symptoms. Other people have symptoms and complications. Pain is the most common symptom. Depending on which of your bones are affected by Paget's disease, you might have other symptoms and complications, such as those listed below.

<b>If you have Paget's disease here:</b>	<b>You may have some of these symptoms and complications:</b>
Pelvis	Pain, arthritis in the hip joint
Skull	Enlarged head, hearing loss, headaches
Spine	Curved spine, back pain, damage to nerves causing such problems as tingling and numbness
Leg	Bowed legs, pain, arthritis in the hip and knee joints

Although rare, the most serious complication of Paget's disease is bone cancer.

## Can Paget's Disease Be Treated?

Yes, Paget's disease can be treated. Finding and treating Paget's disease early is best to prevent complications. The U.S. Food and Drug Administration (FDA) has approved several drugs to treat the disease. Doctors most often prescribe drugs called bisphosphonates. These help reduce bone pain and stop or slow down the progress of the disease. The four bisphosphonates used most often are risedronate (Actonel<sup>1</sup>), alendronate (Fosamax), pamidronate (Aredia), and zoledronic acid<sup>2</sup> (Reclast).

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<sup>1</sup> Brand names included in this fact sheet are provided as examples only, and their inclusion does not mean that these products are endorsed by the National Institutes of Health or any other Government agency. Also, if a particular brand name is not mentioned, this does not mean or imply that the product is unsatisfactory.

<sup>2</sup> Zoledronic acid used to treat Paget's disease outside the U.S. is known as Aclasta; when used for certain cancer treatments, it is called Zometa.

## **Will These Drugs Also Help Improve the Complications I Have From Paget's Disease?**

The drugs may help prevent complications from starting or prevent them from getting worse, but they cannot correct problems that have already set in. In some cases, though, surgery can help. Your doctor can tell you if surgery might be a good idea for you.

## **How Will the Doctor Know If the Drug I Take Is Working?**

Your doctor will probably monitor your progress using two tests: an x ray of your bones and a blood test to measure the level of a chemical called serum alkaline phosphatase (SAP) in your blood. The x rays will show your doctor pictures of how your bones are healing. A decrease in the amount of SAP in your blood will tell your doctor that the disease is less active and you are getting better.

## **Is There a Special Diet I Should Follow?**

There is no special diet to prevent or help treat Paget's disease. For overall bone health, you should eat a balanced diet rich in calcium and vitamin D. The National Academy of Sciences recommends 1,000 mg of calcium daily for adults up to age 50 and 1,200 mg after 50. To help your body use the calcium, the Academy recommends 400 International Units (IU) of vitamin D up to age 70 and 600 IU after 70.

## **What About Exercise? Can I Still Be Active?**

Exercise is important for people with Paget's disease. Being active can help you maintain healthy bones, control your weight, and keep your joints moving. But, you should talk with your doctor before starting an exercise program to make sure what you plan to do is safe and will not put too much stress on the bones that are affected by Paget's disease. For example, your doctor might advise you to try walking instead of jogging if you have Paget's disease in your legs.

## **Do I Need to See a Special Doctor? What Kinds of Doctors Specialize in This Disease?**

The doctor who diagnosed your Paget's disease may be a specialist in the disease. If not, he or she will be able to refer you to someone who is. Doctors who are the most experienced in treating patients with Paget's disease are:

- endocrinologists, who treat hormonal and metabolic disorders, and
- rheumatologists, who treat joint and muscle disorders.

Sometimes other doctors may be needed, such as orthopaedists; neurologists; and ear, nose, and throat specialists. Your doctor will help you find the specialists you need.

## **Will My Children Get This Disease, Too?**

Although Paget's disease does not always run in families, research suggests that a close relative of someone with Paget's disease is seven times more likely to develop the disease than someone without an affected relative. Finding and treating Paget's disease early is important, so some doctors recommend that children, brothers, and sisters of a person with Paget's disease be tested for the disease every 2 to 3 years after the age of 40.

To screen for Paget's disease, a doctor uses the SAP test. If the SAP level is high, suggesting that there might be Paget's disease, the doctor can do a test called a bone scan to learn which bones may be affected. The doctor will then order an x ray of the affected bones to make sure the diagnosis of Paget's disease is correct.

## **Where Can I Go to Get More Information About Paget's Disease?**

There are many good sources of information about Paget's disease. These include:

NIH Osteoporosis and Related Bone Diseases ~ National Resource Center

Tel: 1-800-624-2663

Web: [www.niams.nih.gov/health\\_info/bone](http://www.niams.nih.gov/health_info/bone)

National Institute of Arthritis and Musculoskeletal and Skin Diseases

Tel: 301-495-4484 or 1-877-22-NIAMS

Web: [www.niams.nih.gov](http://www.niams.nih.gov)

National Library of Medicine

Tel: 1-800-272-4787

Web: [www.nlm.nih.gov](http://www.nlm.nih.gov)

The Paget Foundation for Paget's Disease of Bone and Related Disorders

Tel: 1-800-237-2438

Web: [www.paget.org](http://www.paget.org)

Revised January 2008

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### **For Your Information**

This publication contains information about medications used to treat the health condition discussed here. When this fact sheet 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 at 1-888-INFO-FDA (1-888-463-6332, a toll-free call) or visit their Web site at [www.fda.gov](http://www.fda.gov).