Points To Remember About Paget’s Disease of Bone

- Paget’s disease of bone is a chronic (long-lasting) disorder that causes bones to grow larger and become weaker than normal.
- With treatment, many people can manage their symptoms, improve pain, and control the effects of the disease.
- Treatments can include medications, surgery, and lifestyle changes to increase bone health, such as exercise and a diet rich in calcium and vitamin D.
- People with Paget’s disease should maintain a healthy weight, prevent falls, avoid smoking, and only drink alcohol in moderation.

What is Paget’s disease?

Paget’s disease of bone is a chronic (long-lasting) disorder that causes bones to grow larger and become weaker than normal. Usually only one or a few bones have the disease.

Many people with Paget’s disease do not have symptoms. However, the bone changes can cause:

- Bone pain.
- Misshapen bones.
- Broken bones (fractures).
- Problems in the joints near the bones with the disease.

With treatment, many people can:

- Manage their symptoms.
- Improve pain.
- Control the effects of the disease.

Who gets Paget’s disease?

Certain factors may make you more likely to get Paget’s disease:
Age. Paget’s disease is less common in people under age 40. The chance of getting the disease goes up as you age.

- Anglo-Saxon descent. Paget’s disease is more common in certain areas of the world, such as:
  - North America.
  - Australia.
  - New Zealand.
  - Europe, in people of Anglo-Saxon descent.

- Family history. Paget’s disease is common in families.

What are the symptoms of Paget’s disease?

You may not know you have Paget’s disease because many people with the disease do not have symptoms. However, fractures or misshapen bones from the disease may cause pain. Symptoms develop slowly. The disease does not spread to normal bones.

Some people with advanced disease may have misshapen bones and other bone changes, which may include:

- Increase in head size.
- Bow shape of the leg.
- Curving of the spine.

Other symptoms can develop, depending on the bone affected and can include:

- Headaches and hearing loss when Paget’s disease affects the skull.
- Tingling and numbness in arms and legs when enlarged vertebrae (bones that form the backbone) put pressure on the nerves in the spine.
- Hip pain, which may occur when Paget’s disease affects the pelvis or thighbone.

What causes Paget’s disease?

Doctors do not know the cause of Paget’s disease. However, changes in genes increase the chance someone could develop Paget’s disease. Also, certain viruses may cause the disease in people who already have risk factors for Paget’s disease.

Is there a test for Paget’s disease?

Some common tests that doctors order to diagnose Paget’s disease include:

- X-ray. This is the most common test that doctors use to diagnose the disease.
• **Blood test.** A blood test can check for an enzyme in your blood that may be a sign of the disease.

• **Bone scan.** A bone scan is a test that helps doctors identify which bones are affected by Paget’s disease. The test may help your doctor understand the extent of the disease.

How is Paget’s disease treated?

Treatment can help you manage your symptoms but does not cure the disease. The goal of your treatment is to:

• Slow down or stop the changes to your bone.
• Lower your chance of having complications.
• Ease bone and joint pain.
• Repair breaks (fractures).

Doctors may recommend the following to help treat and manage the disease:

• Medications, such as bisphosphonates or calcitonin.
• Surgery to correct problems from the complications of the disease, such as fractures or arthritis that leads to the need for a joint replacement.
• Exercise – such as walking or lifting weights – to build strong bones and help you maintain a healthy weight.
• Diet to ensure you get enough calcium and vitamin D.

Who treats Paget’s disease?

Paget’s disease can affect many parts of the body. You may need to see more than one type of doctor, including:

• Endocrinologists, who treat hormonal and metabolic disorders.
• Rheumatologists, who treat joint and muscle disorders.
• Neurologists, who treat disorders and diseases of the spine, brain, and nerves.
• Orthopaedic surgeons, who treat bone injuries and disease.
• Otolaryngologists, who treat ear, nose, and throat disorders.

Living with Paget’s disease

Current treatments can help most people with Paget’s disease lead productive lives. When you follow your doctor’s treatment plan, you may lower the chance of developing complications or major changes in your bones. You should also:
Maintain a healthy weight, which is particularly important if Paget’s disease has led to arthritis of the hip or knee.

- Prevent falls by:
  - Checking your home for dangers such as loose rugs and poor lighting.
  - Installing grab bars and handrails.
  - Using nonskid mats in the bathroom and tub.
  - Having regular eye exams.
  - Increasing your balance and strength by exercising every day.

- Live a healthy lifestyle to maintain good bone health. Do not smoke, and if you do smoke, quit. If you choose to drink alcohol, do so in moderation.

For more info

U.S. Food and Drug Administration
Toll free: 888-INFO-FDA (888-463-6332)
Website: https://www.fda.gov

Drugs@FDA at https://www.accessdata.fda.gov/scripts/cder/daf. Drugs@FDA is a searchable catalog of FDA-approved drug products.

Centers for Disease Control and Prevention, National Center for Health Statistics
Website: https://www.cdc.gov/nchs

NIH Osteoporosis and Related Bone Diseases ~ National Resource Center
Website: https://www.bones.nih.gov

American Academy of Orthopaedic Surgeons
Website: http://www.aaos.org

American College of Rheumatology
Website: http://www.rheumatology.org

National Osteoporosis Foundation
Website: https://www.nof.org

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- Asian Language Health Information
• Spanish Language Health Information