

Paget's Association

gene ? acute chronic
gait ? osteoclast ? musculoskeletal

P A G E T ' S
J A R G O N
B U S T E R

bisphosphonates scintigram ?
distal ? lateral ? anterior

Paget's Jargon Buster

To help those affected by Paget's Disease of Bone understand the language being used about their care and treatment, the Paget's Association has provided this Jargon Buster. In addition, we have included some terms that may be read in articles regarding Paget's research. We hope you find it useful.

A

Aclasta: A brand name for zoledronate, which is a member of the bisphosphonate class of drugs. It is a treatment given for Paget's disease by infusion into the bloodstream.

Actonel: A brand name for risedronate tablets, which can be used to treat Paget's disease. Risedronate is a member of the bisphosphonate class of drugs.

Acute: Used to describe a disorder or symptom that comes on suddenly and needs urgent treatment.

Adjacent: Next to.

Adverse reaction: Side effect of a drug or treatment.

Alkaline phosphatase (ALP): A blood test for ALP levels may be carried out as part of a liver function test (LFT). ALP is present

in many cells within the body, but particularly in liver and bone cells. If there is overactivity of bone cells due to Paget's disease, ALP is released and can be measured. When Paget's disease is active, the ALP level will often, but not always, be raised.

Analgesia: Medication used to relieve pain.

Anterior: The front, as opposed to the posterior e.g., the anterior surface of the heart is toward the breastbone (the sternum).

Arthrodesis: The joining (fusion) of two bones.

Axial skeleton: The part of the skeleton that includes the bones in the centre of the body, including the bones of the skull, neck, spine, ribcage, sternum and sacrum, which are areas commonly affected by Paget's disease.



Banana fracture: A complete, horizontal pathological (caused by a disease, rather than injury) fracture, which can occur in deformed bones affected by Paget's disease.

Basic research: Research that seeks to understand processes that go wrong in cells, for example in a disease.

Beta crosslaps: A bone turnover marker, which measures bone breakdown activity.

Bilateral: Affecting both sides.

Bisphosphonates: A group of drugs that slow down the activity of the cells that break down bone (osteoclasts). They are used in the treatment of osteoporosis, Paget's disease and other conditions.

Blade of grass sign: Also known as the 'candle flame sign', this refers to how Paget's may appear on an x-ray of a long bone, such as the thigh bone (femur).

Blood test: A small sample of blood is taken from a vein for testing by laboratory scientists.

Bone: Bone is living tissue that makes up the body's skeleton. Providing support for the body,

protecting our vital organs, and allowing us to move, bones also provide an environment for bone marrow, where the blood cells are created, and act as a storage area for minerals, such as calcium.

Bone biopsy: The removal of a piece of bone tissue for examination by a pathologist.

Bone remodelling: Bone is living tissue, which is renewed and replaced throughout life. This process is known as bone remodelling (or bone metabolism) and is important in maintaining a healthy skeleton. It ensures that old or damaged bone is removed from the skeleton and replaced with new healthy bone tissue. It is this process that is disrupted in Paget's disease.

Bone markers: These measure bone cell turnover, which is the process of bone tissue being broken down, and new bone being built (see 'bone remodelling' above).

Bone metabolism: A continual cycle of bone renewal and repair. Normal bone metabolism enables bones to repair microscopic damage and maintain their strength. It is this process that is disrupted in Paget's disease. See 'bone remodelling' above.

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Bone scan: A radionuclide bone scan, also known as a scintigram, isotope bone scan or nuclear medicine bone scan, can determine which bones have Paget's disease and how active the disease is. The scan involves an injection into a vein, of a small and safe amount of a mildly radioactive chemical called an isotope. This travels to the bones via the bloodstream and after around 3 hours a 'gamma' camera scans the skeleton to produce an image. Abnormal bone absorbs more radioactivity than normal bone, so these areas will be highlighted in the scan results.

Bone turnover: Also known as bone remodelling. The skeleton is continually renewing itself. Bone cells (osteoclasts) break down old bone (bone resorption) and other bone cells (osteoblasts) lay down new bone (bone formation). This process of renewal is often described as bone turnover.



Calcitonin: A naturally occurring hormone secreted by the thyroid gland. Calcitonin is involved in helping regulate levels of calcium and phosphate in the blood. When used as a treatment, calcitonin

can sometimes help relieve pain associated with Paget's disease (available in an injection or nasal spray).

Calcium: A mineral found in many foods. Calcium is used by the body to help strengthen bones and teeth.

Candle flame sign: Also known as the 'blade of grass sign'. This refers to how Paget's may appear on an x-ray, in a long bone such as the thigh bone (femur).

Cartilage: A connective tissue that acts as a shock-absorber between bones.

Cervical spine: The neck area of the spine.

Cholecalciferol: Also known as vitamin D3, this is a type of vitamin D that is made by the skin when exposed to sunlight. It is also found in some foods and can be taken as a dietary supplement.

Chronic: A condition that persists for a long time.

Clavicle: The collar bone.

Clinical research: Research that typically involves patients and volunteers.

Closed fracture: A break in a bone where the skin remains unbroken.

Comminuted fracture: A bone is broken into several pieces.

Comorbidity: More than one disease or condition is present in the same person at the same time. Conditions described as comorbidities are often long-term conditions.

Consultant: The most senior grade of hospital doctor.

Contraindication: A situation where a particular treatment should not be used.

Cotton wool appearance: The disorganised bone of Paget's disease can appear as 'cotton wool' on an x-ray. Also referred to as the 'jigsaw pattern' or 'mosaic pattern'.

CT (or CAT) scan: Computed (Axial) Tomography. A diagnostic imaging technique that creates detailed pictures of the inside of your body. It takes pictures from different angles and puts them together to make a 3-dimensional image.

D

Deficiency: Lack of something.

DEXA scan: Dual Energy X-ray Absorptiometry. Also known as a bone densitometry scan, it uses low dose x-rays to take measurements to work out the strength (density) of your bones. If your bone density is lower than normal for your age, it

indicates a risk for osteoporosis and bone fractures. It is not a test used to diagnose Paget's disease.

Diaphysis: The shaft of a 'long bone' such as the thighbone.

Displaced fracture: A break in a bone where the parts of the bone no longer line up correctly.

Distal: When used to describe the skeleton, distal means a position that is the furthest from the body. For example, the femur (thighbone) is attached to the body at the hip and so the distal part of the femur is the part of the bone furthest from the hip, which is the part nearest to the knee joint.

DNA: Did Not Attend – as in missed an appointment.

DNA: In genetics DNA is deoxyribonucleic acid, which makes up our genes.

E

ECT: Enhanced Care Team.

Effusion: When referring to a joint, an effusion is the abnormal accumulation of fluid in or around a joint and is associated with swelling, pain and stiffness.

EHR: Electronic Health Record.

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EPR: Electronic Patient Record.

Extension: A movement that increases the angle between two body parts, such as straightening the leg out.

F

Femur: Thigh bone.

FH: Family History.

Flexion: A movement that decreases the angle between two body parts, such as bending the arm.

Fracture: A broken or cracked bone.

Fusion: The joining of two bones. Also known as arthrodesis.

FBC: Full Blood Count.

G

Gait: The manner or style of walking. Paget's disease can sometimes alter a person's gait e.g. if the leg is bowed.

General Practitioner (GP): Your local doctor, who can help you directly and refer you for specialist care or assessment when necessary.

Gene: The basic unit of genetics. Genes influence what we look like on the outside and how we work

on the inside. Genes are made of a chemical called deoxyribonucleic acid (DNA).

Genetic mutation: A genetic mutation is a mistake in the DNA code that spells out the instructions coded by genes. These mistakes can be harmless and make us who we are, but sometimes they can cause health problems. Some genetic mutations are inherited.

Genetic predisposition: A genetic predisposition means that a person's gene code has given them an increased chance of developing a certain disease.

Genetics: The study of inherited characteristics, which determine a person's appearance and how our body works.

I

Insufficiency fracture: A type of stress fracture, which is the result of normal stresses on abnormal bone.

Isotope bone scan: A radionuclide bone scan, also known as a scintigram or nuclear medicine bone scan, can determine which bones have Paget's disease and how active the disease is. The scan involves an injection into a vein of a small and safe amount of a mildly

radioactive chemical called an isotope. This travels to the bones via the bloodstream and after around 3 hours a 'gamma' camera scans the skeleton to produce an image. Abnormal bone absorbs more radioactivity than normal bone, so these areas will be highlighted in the scan results.



Jigsaw pattern: The disorganised bone of Paget's disease can appear as a 'jigsaw pattern' on an x-ray. Also referred to as the 'cotton wool' or 'mosaic pattern'.

Joint: The junction between the ends of two adjacent bones.



Kyphosis: An increased curvature of the thoracic spine.



Lateral: A term for structures furthest from the midline of the body.

LFTs: Liver Function Tests.

Lumbo-sacral region: The lower back.



Mosaic pattern: The disorganised bone of Paget's disease can appear as a 'mosaic pattern', also referred to as a 'jigsaw pattern' or 'cotton wool'.

MRI scan: A Magnetic Resonance Imaging scan uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

Multi-disciplinary team (MDT):

A multi-disciplinary team is a team made up of various healthcare professionals with differing skills and areas of expertise, to ensure patients receive the best possible treatment and care.

Musculoskeletal (MSK) conditions:

A broad range of conditions affecting bones, joints and muscles.



NAD: Nothing Abnormal Detected/Discovered.

NSAIDs: Non-Steroidal Anti-Inflammatory Drugs.



OA: Osteoarthritis.

Occupational therapist (OT): The professional who works with people to develop skills and confidence in everyday activities.

Open fracture: This is when the broken bone pierces the skin. Also known as a compound fracture.

Orthopaedic surgeon: A specialist doctor who carries out operations on bones, such as a hip replacement.

Orthotics: The general term for the design and the use of artificial devices such as splints, braces and insoles, designed to help patients with certain medical conditions.

Orthotist: A skilled professional who applies orthotic devices to improve function.

Osteoblast: A type of cell responsible for producing bone tissue.

Osteoclast: A type of cell that removes old bone tissue.

Osteocyte: A cell involved in the maintenance of bone. Osteocytes also regulate the functions of other bone cells.

Osteoarthritis (OA): A condition that causes the joints to become painful and stiff. It mainly affects the joint cartilage and the bone tissue next to the cartilage. It is the most common form of arthritis in the UK.

Osteonecrosis of the jaw (ONJ): A rare condition in which normal healing of the jawbone does not occur. This can happen after an invasive dental procedure, such as having a tooth removed.

Osteosynthesis: The uniting of a broken bone by mechanical means, e.g. with screws and a plate.

Osteotomy: A surgical procedure in which a bone is cut and realigned (as to correct a deformity such as a bowed leg).



Paget's Disease of Bone (PDB): Paget's disease is characterised by abnormalities in the bone's renewal and repair process (known as remodelling). It is often simply known as Paget's disease.

PDB: Paget's Disease of Bone.

Picture frame vertebrae: This refers to how Paget's disease may appear on an x-ray when bones (vertebrae) in the spine appear thickened due to Paget's disease.

Pathological fracture: A fracture caused by a disease, rather than injury.

Pathology: The study of disease processes and the name given to any tissue damage due to dysfunction or disease.

Pelvis: The pelvis is the part of the body between the abdomen and the thighs. The term 'pelvis' can refer to the pelvic skeleton (also known as the pelvic girdle), which is the skeleton in the lower part of the trunk. The bones form a bowl-shaped structure to which the thighbones and spine are joined

Placebo: A placebo is a substance or treatment which is designed to have no therapeutic value. The placebo effect is, for example, where a person feels their condition has improved due to taking a tablet, even though the tablet contained no active drugs.

PMH: Past Medical History.

Posterior: Toward or situated at the back. The opposite of anterior.

Primary care: Primary care services provide the first point of contact in the UK healthcare system, acting as the 'front door' of the NHS. Primary care includes general practice, community pharmacy and dental services.

PRN (pro re nata): As required.

Proximal: The nearest point to the body, e.g. the proximal end of the femur is part of the hip joint.

Pseudofractures: The result of normal stresses on abnormal bone. It is a type of insufficiency fracture, which is a type of stress fracture.

P1NP: Type 1 procollagen peptide – a bone turnover marker. P1NP is a measure of how much bone is being made.



Radiograph: An x-ray image.

Radiographer: A professional who prepares and produces x-rays for a radiologist.

Radiologist: A doctor who specialises in radiology and diagnostic investigations such as x-ray, MRI and CT.

Randomised Controlled Trial (RCT): A type of scientific experiment using random allocation of different treatments to participants, to ensure that the effectiveness of the treatment is not just due to the placebo effect.

Rheumatologist: A doctor who specialises in the diagnosis and treatment of diseases of the joints, muscles, and bones.

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Reclast: A brand name for zoledronate, which is a member of the bisphosphonate class of drugs. It is a treatment given for Paget's disease via an infusion into the bloodstream.

Referred pain: Pain that is felt in a different location from that of the cause.

Radionuclide bone scan: Also known as a scintigram, isotope bone scan or nuclear medicine bone scan, it can determine which bones have Paget's disease and how active the disease is. The scan involves an injection into a vein of a small and safe amount of a mildly radioactive chemical called an isotope. This travels to the bones via the bloodstream and after around 3 hours a 'gamma' camera scans the skeleton to produce an image. Abnormal bone absorbs more radioactivity than normal bone, so these areas will be highlighted in the scan results.

Risedronate: A drug that can be used to treat Paget's disease. It is a member of the bisphosphonate class of drugs.

Risk factor: Anything that increases a person's chances of developing a disease.

ROM: Range of Motion.



Sabre tibia: This refers to the x-ray appearance of a bowed tibia (shinbone) resembling the curve of a sabre.

Scintigram: Also known as a radionuclide bone scan, an isotope bone scan or nuclear medicine bone scan, it can determine which bones have Paget's disease and how active the disease is. The scan involves an injection into a vein of a small amount of a mildly radioactive chemical called an isotope. This travels to the bones via the bloodstream and a 'gamma' camera then scans the skeleton to produce an image. Abnormal bone absorbs more radioactivity than normal bone, so these areas will be highlighted in the scan results.

Sclerotic: Hardening or thickening of bone.

Secondary care: Specialist care, typically, but not always, provided in a hospital.

Spinal stenosis: Narrowing of the canal housing the spinal cord, commonly caused by encroachment of bone.

Spine: Column of 33 vertebrae extending from the base of the skull to the tip of the coccyx.

Sternum: Breastbone.

Stress fracture: A small crack in a bone. Sometimes known as a hairline fracture.

Surgeon: A doctor who specialises in performing operations.



Tam o'Shanter sign:

A "Tam o'Shanter" is a Scottish hat. When the skull is x-rayed, the appearances of Paget's disease can sometimes be similar in shape to that of the hat, therefore, this is known as the 'Tam o'Shanter sign'.

Tertiary care: Healthcare provided in specialist centres. Consultants in tertiary care centres may have access to more specialised equipment and expertise for a particular condition. Referrals to tertiary services are usually made by your GP or a healthcare professional at your local hospital.

THR: Total Hip Replacement.

Tibia: Shinbone.

TKR: Total Knee Replacement

Translational research: The process of taking the findings from basic science and turning them into something that will be useful for patients, such as a new treatment or a new test for a particular condition.



Vertebra: One of the 33 bones that make up the spine.

Vertebrae: The interlocking bones that form the spinal column.

Vitamin D: This helps regulate the amount of calcium and phosphate in the body. It is needed to keep bones, teeth and muscles healthy.



X-ray: An x-ray is a widely used diagnostic test to examine the inside of the body. X-rays are an effective way of detecting problems with bones, such as fractures.



Zoledronate: Also known as zoledronic acid. This is a member of the bisphosphonate class of drugs and is a treatment given for Paget's disease via an infusion into the bloodstream.

Zoledronic acid: See 'zoledronate' above.

Zometa: A brand name for zoledronate. See 'zoledronate' above.



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