APE FACT SHEET

OSTEOGENESIS IMPERFECTA

DEFINITION:

Osteogenesis imperfecta is a genetic disorder that is characterized by bones that break easily, often from little or no apparent cause. One of the known causes in some cases is a defect in how the body produces collagen. Collagen is the major protein of the connective tissue. The defect causes the bones and cartilage to be soft and brittle. It also causes the ligaments and skin to be hyperextensible and elastic. There is no present cure for this disorder only treatment to manage it. A student should receive a written consent from a physician before participating in physical activities.

CAUSES OF PAIN:

- Vertebral collapse
- Contractors
- Multiple fractures
- Deformity/malalignment of limbs

CHARACTERISTICS OF PAIN:

- Acute or chronic
- Can be caused by muscle tension, spasm, weakness, and stiffness
- Response can cause one to try and prevent movement of the injured part
- Elevated heart rate

CONSIDERATION AND TEACHING TIPS:

- Avoid activities that involve high impact, jumping, twisting, turning, and even contact with others. The water allows more movement without this risk.
- Play activities with soft equipment to reduce possible contact.
- Due to brittle bones activity level is low therefore most likely their cardiovascular ability is low, make activities appropriate for their capacity.
- During transfer be careful to place <u>pressure over the trunk</u> to support student, avoiding undue pressure on the limbs.

- Joint deformity
- Osteoarthritis
- Recurrent abdominal pain



SUGGESTED ACTIVITIES:

- Range of motion
- Strengthen muscles
- Swimming

- Improve stamina
- Body awareness
- Improve posture
- Awareness on how to keep oneself safe in his/her environment

TREATMENT:

The focus of treatment is controlling the symptoms. A key element is to develop bone mass and muscle strength. This will in turn reduces chance of fractures. Work on maximizing mobility. Many students with osteogenesis imperfect use a wheelchair. A proper nutritious diet also helps with body strength.

PAIN MANAGEMENT:

- Interdisciplinary approach to pain management can produce the best results to reduce pain.
- Relaxation training may help reduce tension from muscles and in turn help reduce pain.
- Visual imagery or distraction.
- Heat can help with chronic pain or muscle stiffness.
- Ice can help numb the pain area and prevent swelling.
- Apply heat or ice for 15 to 20 minutes.
- Massage therapy
- Individual or family therapy with a focus on depression, anger, frustration.
- Psychological management has been effective on pain tolerance.

Information on this sheet contains only suggested guidelines. Each student must be considered individually, and in many cases, a physician's written consent should be obtained.