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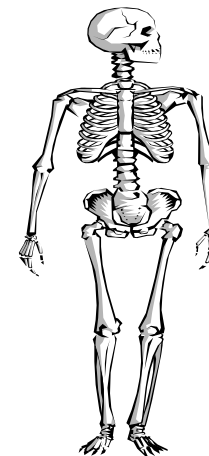
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**CHILDREN'S HOSPITAL WESTMEAD.
CENTRE FOR CHILDREN'S BONE HEALTH**

BISPHOSPHONATE TREATMENT and RESEARCH PROGRAMS



**PARENTS
INFORMATION
BOOKLET
2006**

INTRODUCTION.

Bisphosphonates are a group of drugs which have been used world wide for over 25 years in adults and over 15 years in children to treat osteoporosis.

At the CHW over 200 children have been treated for osteoporosis with bisphosphonates since 1994 with favourable results in the treatment of osteoporosis.

WHAT IS OSTEOPOROSIS?

Osteoporosis occurs when there is a decreased amount of bone due to either a decrease in the action of the bone forming cells (osteoblasts) or an increase in the action of the bone resorbing cells (osteoclasts). Children with osteoporosis may have bone pain, decreased mobility and increase tendency to fracture.

Osteoporosis can be either congenital (born with) and acquired (due to another condition). Both these forms of osteoporosis are being seen more and more in childhood and if untreated, may result in bone problems in adult life.

Osteogenesis Imperfecta (Brittle Bones) is an example of a congenital osteoporosis. Osteoporosis is a frequent problem in many other congenital bone disorders and neuromuscular disorders. Many of these disorders have been treated at CHW with Bisphosphonate Therapy (BT).

Causes of acquired osteoporosis include certain medications (e.g. Prednisone) and a decreased ability to walk (e.g. Duchenne Muscular Dystrophy and Cerebral Palsy). In any one child there are often a number of causes working together.

Disclaimer:

This information sheet is for education purposes only. Please consult with your doctor or other health professional to make sure this information is applicable to your child.

HOW LONG WILL YOUR CHILD BE IN HOSPITAL?

Both Pamidronate and Zoledronate are given into a vein via a drip. Because of this, your child will need to be admitted to the hospital. Most children can have their treatment as a day stay patient and are admitted to our day ward, Turner Ward. With the first treatment, some children will need to remain in hospital for 2-3 days. Your doctor will let you know if your child will need to stay in hospital

ON THE DAY OF YOUR CHILD'S TREATMENT:

On the admission date go to the "Enquiry Desk" in the main entrance to the Hospital. The staff at the Enquiry Desk will direct you to Turner Ward. If your child is staying overnight, you to the ward your child will be admitted to.

If your child is having Zoledronate, they will be in the ward about 1 hour before going home. If your child is having Pamidronate, they will be in the ward about 4 hours.

WHAT HAPPENS AFTER YOUR CHILD'S TREATMENT?

After your child's treatment the nurse co-ordinator will give you the time of his/her next treatment and the times of any other tests or appointments that are needed.

WHY DO WE USE BISPHOSPHONATES?

We use bisphosphonates for different reasons depending on the medical problem your child has.

1. **Osteoporosis:** If your child has osteoporosis (too little bone), we use bisphosphonates to increase the amount of bone he/she has over the whole skeleton. This will make the bones stronger and decrease bone pain.
2. **Perthes Disease / Avascular Necrosis:** If your child has Perthes disease of avascular necrosis (AVN), we use bisphosphonates to slow the taking away of the bone that has lost its blood supply. This will allow new bone to form over the old bone and the bone will keep its normal shape. By doing this, we hope to be able to keep the bone / joint working normally.
3. **Slow Bone Healing:** If your child has slow bone healing it is often because the bone made at the fracture site is being taken away too quickly. We use bisphosphonates to slow down the speed at which the new bone is taken away. This allows time for the fracture to heal.

WHICH BISPHOSPHONATE TO USE

We use Pamidronate in children with moderate to severe Osteogenesis Imperfecta and for very young children. Because Pamidronate is used in many other hospitals in New South Wales, we will also use this drug if treatment will be continued at another hospital.

Most other children getting IV treatment tend to get Zoledronate.

We will occasionally suggest your child has a tablet form of bisphosphonate; Risedronate (Actonel) or Alendronate (Fosamax). Your doctor will talk with you about the best treatment option.

WHEN SHOULD BISPHOSPHONATES NOT BE GIVEN?:

1. **Pregnancy:** Bisphosphonates cross the placenta and can affect an unborn baby. They must therefore not be given to a pregnant women. We therefore do a pregnancy test before each dose of bisphosphonate in females of reproductive age.
2. **Low Blood Calcium or Vitamin D Level:** Bisphosphonates cause the blood calcium level to drop. It is not safe to give it to someone who already has a low blood calcium or vitamin D level.

WHAT ARE THE COMPLICATIONS OF BISPHOSPHONATES?

1. **'Flu-like Symptoms:** Just about every child feels like they have the 'flu i.e. fever, sick in the stomach, vomiting, headache, body aches and pains, about 24 hours after they get their first dose of bisphosphonate. Not every child gets all of these symptoms and they are usually gone within 2-3 days. Giving regular Paracetamol every 4 hours or Nurofen every 8 hours, usually makes your child feel better. Some children will be given Prednisone to decrease these symptoms even more. It is very unusual for these symptoms to occur with the following doses of bisphosphonate. It is best to expect that your child will be too sick to go to school for about 3 days after his/her first dose of bisphosphonate.
2. **Low Blood Calcium Levels:** This is seen most often after bisphosphonates are given for the first time. Very rarely, the blood calcium can drop to very low levels and cause problems with the way the nerves and muscles work. To make sure the blood calcium does not drop too low, we give all children extra calcium and vitamin D for 3 days after the first bisphosphonate dose and do blood test 48 and 72 hours after the first dose of bisphosphonate is given.

Your child might need to have some extra calcium and vitamin D for one to two weeks before his/her first treatment.

3. **Osteonecrosis of the Jaw:** There have been a number of reports of jaw bone problems in adults who have been treated with bisphosphonates. It has never been seen in children. To decrease the chances of children having problems with their jaw, treatment should be stopped for a period of time if a tooth is going to be taken out by a dentist. It does not need to be stopped if teeth are falling out naturally.
4. **Slow Bone Healing:** If your child is on bisphosphonates their bone healing might be slowed down. After a fracture or bone operation your child's doctor might stop treatment until the bone has healed.

PRIOR TO YOUR CHILD'S TREATMENT:

The Co-ordinator of the Bisphosphonate Treatment program will arrange several investigations eg urine and blood collection, renal ultrasound and DEXA scan (bone density scan) for your child and an appointment to be seen by the endocrinologist or geneticist before they commence the program.

You will be given the date and times for your child's infusion in advance by the coordinator.

The hospital will send you admission papers for you to sign and return to them.