

Pamidronate: A guide for families

Pamidronate is a medicine given through an IV infusion that helps increase bone density.

What is pamidronate?

Pamidronate belongs to a group of medicines called bisphosphonates. These medicines are used to slow down normal bone breakdown, which allows bone mass to increase. Pamidronate is used in children with low bone mineral density and fractures. This can be from conditions such as osteogenesis imperfecta, cerebral palsy, lysosomal storage diseases and other conditions, and taking medicines that lead to fragile bones.

Pamidronate is approved by the FDA to treat conditions including Paget's disease of the bone, osteoporosis and other conditions in adults. While no bisphosphonate medicine has been approved by the FDA for use in children, we usually use pamidronate because it has been the most used in children.

How is pamidronate given?

Pamidronate is given as an infusion through a needle placed into your child's vein. Your child will get this medicine in the Seattle Children's infusion center, or at another approved infusion center.

Our treatment plans start with a standard dose based on your child's age and weight. We give infusions for most children with osteogenesis imperfecta according to the chart below.

Age	Dose per kg of weight	Length of treatment
Under age 2	.5 mg	3 days in a row, every other month
Age 2 to 3	.75 mg	3 days in a row, every 3 months
Over age 3	1 mg	3 days in a row, every 4 months

For children with other causes of osteoporosis, we typically follow this plan: 1 mg per kilogram of body weight, 1 day every 3 months.

Bisphosphonates are not broken down and removed from the body like most medicines. Fifty percent of the bisphosphonate goes directly to the bone, and 50 percent is passed out in the urine.

Studies are being done to measure how long bisphosphonates stay in the bones. We will adjust your child's dose and infusion rate based on their age and how much pamidronate they have had before.

Bisphosphonates are not given to patients who are pregnant or who are considering becoming pregnant.

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To Learn More

- Orthopedics
206-987-4179 or
206-987-2687
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.



We evaluate the health of your child and try to reduce the risks and possible side effects when receiving this medicine.

Before starting pamidronate, your child will need to have the following:

- Blood work, including calcium and vitamin D levels and kidney function
- An EKG (a test that checks for problems with the electrical activity of your heart)
- An appointment with their dentist to discuss any upcoming dental work
- A DXA bone mineral density test

What are the side effects of pamidronate?

The most common side effects seen with the first few infusions are flu-like symptoms including:

- Fever
- Nausea
- Throwing up
- Head and body aches and pains

These symptoms often occur within the first 12 to 24 hours after the infusion. Most of the time, they go away within 48 hours. Some children have aches and pains lasting up to 7 days. Give your child Tylenol or ibuprofen to help make them more comfortable only if recommended by your healthcare provider.

These symptoms will decrease with each subsequent infusion.

Other side effects may include:

- Changes in blood electrolytes (calcium, phosphate, potassium and magnesium)
- Decreased white blood cell counts
- Anemia
- Problems controlling fluid balance and blood pressure

Most of these side effects can be easily watched and treated. When starting pamidronate, your child will be placed on calcium supplements to help maintain the level of calcium in the blood. Some babies have reacted with decreased blood cells, but these return to normal within 2 to 3 days.

Respiratory distress has been reported in children less than age 2 years with their first infusion. For this reason, we admit children under age 2 to the hospital for their first 1 or 2 infusions.

If your child has had an osteotomy (cutting of the bone for correcting deformities), we will stop giving them the pamidronate for 3 months after their procedure. This is because pamidronate may cause bone healing to be slower.

Other side effects to watch for during the infusion and at home

Let your doctor or infusion nurse know if your child has any of the following:

- Painful or difficult urination
- Urinating less than normal or not at all
- Urinating more than normal
- Swelling
- Rapid weight gain
- Confusion, hallucinations, unusual thoughts or behavior
- Feeling like they might pass out
- Pale skin, easy bruising or bleeding
- Seizures (convulsions). Risk of seizures with pamidronate is increased in children who have a history of seizure disorder prior to starting treatment.
- Eye pain, vision changes, increased sensitivity to light
- Uneven heart rate
- Extreme thirst
- Leg discomfort, muscle weakness or limp feeling
- Mild heartburn
- Upset stomach, loss of appetite
- Gas
- Diarrhea (loose bowel movement)
- Constipation
- Runny or stuffy nose
- Cough
- Increased sweating
- Numbness or tingly feeling
- Pain, burning, swelling or irritation around the IV needle
- Dizziness
- Drowsiness, weakness, or tired feeling

Even if your child has these symptoms, you should still plan on coming for their next scheduled therapy.

What are possible long-term side effects for my child?

Long-term studies are still needed to understand the long-term effects on children. The side effects listed below have only been seen in adults taking bisphosphonate medicines.

- Jaw cysts or necrosis (dissolution of bone around teeth after major dental procedures)
- Atrial fibrillation (rapid uncoordinated contractions of the atria of the heart, resulting in a lack of synchronism between heartbeat and pulse beat)
- Abnormal EKG
- Fracture of the femur where bone has become too dense or brittle

How long does my child need to stay on pamidronate?

Before their first pamidronate infusion, your child will have a DEXA bone density scan, blood tests and an EKG. They will then have yearly return visits to the clinic to repeat these tests. These tests help us to plan your child's dose and length of treatment.

After your child has two years of infusions, we will evaluate their dosage levels for their treatment plan. If we see that your child is ready to decrease their treatments, they will have one day of infusions every six months. Their dose will be 1 mg of pamidronate per kg of weight until they stop growing (the plan will differ for each child).

While some children taking bisphosphonates are reported to have reached normal bone density, we don't know how your child will respond to the treatment.

The most important goals of pamidronate treatment are reduction in the number of fractures, alleviating bone pain, and improving comfort.

Increased bone density does not necessarily mean increased bone strength. Bone density is just one aspect that is modified by this medicine. Pamidronate can also reduce pain.

What can we expect during my child's visit to the hospital?

- Park and enter the hospital from the Ocean garage. Entrance coordinators will give you a badge and directions for check-in at the Infusion Unit in the Cancer and Blood Disorders Center.
- All of your child's vital signs will be taken. This includes temperature, pulse, respiratory rate (breathing rate) and blood pressure. These will be taken before and after each infusion.
- The nurses in the infusion unit will start an IV that will stay in for the 3 days of the infusion. They will teach you how to take care of the IV.
- Your child may receive Tylenol and Benadryl prior to the infusion.
- Your child will be asked to stay seated in an armchair during the infusion. The standard infusion lasts 4 hours if there are no signs of reaction. The length of infusion can be adjusted if needed.
- Tell the nurse if your child has flu-like symptoms during the infusion and they will be given medicines as needed.
- After the infusion, follow the nurses' instructions for care of the IV access overnight including IV supplies.

What to bring:

- Books, toys or other items to distract your child. A TV is provided, so feel free to bring DVDs.
- Pack a snack for your child. Seattle Children's has a cafeteria that is open to families during the day.

Metabolic Bone Clinic cancellation policy

If, more than twice, you either cancel your visit within 24 hours of your first infusion, or do not come on the day you are scheduled, you must schedule a new appointment with the doctor. We cannot schedule additional pamidronate infusions until your child has been seen.

Additional resources

The Osteogenesis Imperfecta Foundation
oif.org/site/PageServer?pagename=Pamidronate
MedicineNet.com
medicinenet.com/pamidronate-injection/article.htm