



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Pamidronate infusions for osteogenesis imperfecta (OI)

This information sheet from Great Ormond Street Hospital (GOSH) explains about pamidronate infusions for osteogenesis imperfecta (OI), how it works and what to expect when your child comes to GOSH for the infusion.

What is a pamidronate infusion and why does my child need one?

Pamidronate is a type of bisphosphonate, which is a medicine that prevents loss of bone mass. Bisphosphonates have been used for a variety of conditions in childhood where there is bone pain and immobility in association with osteoporosis and/or abnormal bone formation. Pamidronate strengthens the bone by increasing bone density and corrects the imbalance between bone reabsorption and bone formation which occurs in osteogenesis imperfecta (OI).

Pamidronate infusions are most effective when they are given every six weeks in small children and three-monthly in older children. This may be reduced during or after puberty as the bone density may improve. We currently recommend continuing pamidronate treatment throughout childhood until growth is completed. Stopping treatment may potentially increase risk of fracture.

Are there any alternatives?

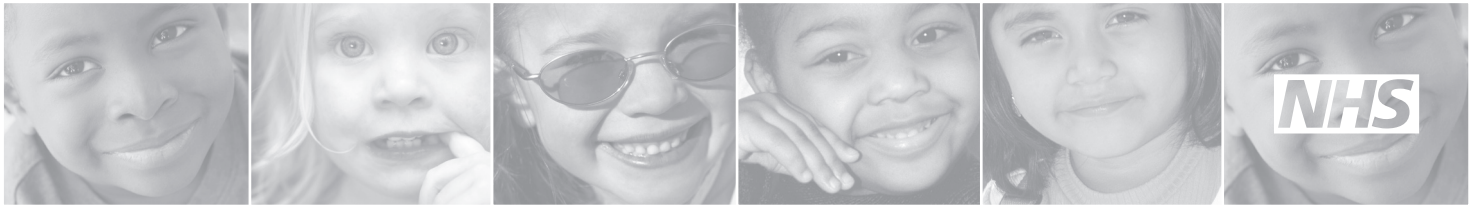
Bisphosphonate treatment strengthens bone reducing risk of fractures. In older adolescents there is a bisphosphonate tablet available called risidronate, which may be suggested instead of the pamidronate infusions. However this will be discussed with your consultant before starting.

What happens before the infusion?

You will already have received information about how to prepare your child for the blood test in your admission letter.

When you arrive on Kingfisher Ward in the morning, a nurse will check your child and take some baseline observations of their temperature, pulse and breathing. These will be used to monitor your child during the infusion.

They will also take a blood sample for testing and insert a cannula (thin, plastic tube) into a vein, usually on the back of the hand or inside the elbow, so that the infusion can be given easily. If your child has had problems with needles in the past or is scared, please tell your nurse. If your child has a central venous access device, such as a central venous catheter or implantable port, this will be used to take the blood sample and infuse the pamidronate instead of a cannula.



In the afternoon, once the results of the blood test results are back and checked by a doctor, a nurse will start the pamidronate infusion.

What does the infusion involve?

The pamidronate is usually in a plastic bottle with a tube connected to your child's cannula. It will be infused gradually over four to six hours every 24 hours, giving three doses in total. The last infusion will usually finish in the evening of the third day of your child's admission. When the last infusion has finished, the nurses will check that your child is well enough to go home and remove the cannula or port needle.

Are there any risks or side effects?

Each person reacts differently to medicines, so your child will not necessarily experience every side effect mentioned. If you are concerned about any of these side effects, please ask your doctor, nurse or pharmacist. Side effects of pamidronate commonly include:

- **Flu-like symptoms including a high temperature, aches/pains and vomiting** – This affects the majority of children for 24 to 48 hours on day two of their first set of infusions. The nurses will give your child medicine to deal with symptoms as they occur. If they are severe, the third infusion may be delayed. This side effect does not usually happen with following infusions.
- **Low calcium levels** – Calcium levels tend to drop over the first infusion course. This usually causes no symptoms but if it occurs, we will give your child double calcium supplements

in the form of dispersible tablets for a few days. Low calcium levels are usually diagnosed through blood tests, however in very rare circumstances, it can cause your child to have a small rise in blood pressure and shakiness in their hands

- **Delayed bone healing** – This is a potential risk after orthopaedic surgery. If your child requires surgery, we will usually reschedule their pamidronate infusion so that there is a gap of at least **two weeks** before and after surgery or until there is evidence of bone healing confirmed on an x-ray.

What happens afterwards?

We will inform you in clinic when your child's next follow up with us will be. When your child has had their infusion on Kingfisher ward, we will aim to give you their next admission date before you are discharged.

Dose regimes maybe modified depending on monitoring investigations and results of annual DEXA scans if your child weighs more than 10kg.

When you get home, call your children's community nursing team if you have any concerns about your child's implantable port, or your family doctor (GP) if you have any general concerns.

If your child has a fracture or you suspect one, please attend your local Accident and Emergency (A&E) department and ask the nursing staff or medical team to call the OI team to let us know or if they require any advice.



**If you have any questions, please contact the Clinical Nurse Specialist
for Osteogenesis Imperfecta on 020 7405 9200 ext 5824
or Kingfisher Ward on ext 5784.**

Notes

Compiled by the Osteogenesis Imperfecta team in collaboration
with the Child and Family Information Group

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