

FMS for infants with achondroplasia

This leaflet gives more information about FMS (foramen magnum stenosis) for infants with achondroplasia. If you have any questions or concerns, please speak to a doctor or nurse caring for your child.

What is foramen magnum stenosis (FMS)?

The foramen magnum is the opening found at the bottom of the skull which the spinal cord passes through into the spine. Stenosis of the foramen magnum means that this opening is narrower.

Every young child with achondroplasia has some degree of FMS. For about 1 in every 4 patients the narrowing is mild, for another 1 in 4 it is moderate. For the remaining half it is severe, meaning the opening is so narrow, the spinal cord is being squeezed or kinked.

When FMS can be a problem

Infants under 2 years old have a greater risk of problems from FMS. Severe FMS can cause breathing problems, impaired mobility (delays in crawling and walking) and failure to gain weight. Some children have no symptoms at all.

Rarely, infants can stop breathing (cardio-respiratory arrest). As a precaution, parents or carers will be given basic life-support training so that you know what to do in the unlikely event of this happening.

How we monitor FMS

We recommend that every infant with achondroplasia has an MRI scan of the brain and spine shortly after birth. These help us assess the degree of stenosis (narrowing). We might recommend more than one scan, because the degree of stenosis can change as your child grows. Your consultant will tell you when the next scan is recommended.

Every year we will also arrange sleep studies to see if their breathing is impacted by FMS. If it is, they might need to be referred to the respiratory (breathing), or ear, nose and throat (ENT) teams.

Your child's physical and neurological examinations, and their growth measurements, also form a key component of assessing for FMS. These will be done during your child's clinic appointments.

You can read about **having an MRI at Evelina London**, or ask a doctor or nurse caring for your child for a copy.

Symptoms of FMS

There are different symptoms of FMS in infants, but some infants do not show any symptoms at all. Possible symptoms include:

- breath-holding or gasping breathing while asleep
- significant snoring while asleep
- limb weakness, or asymmetric movements (favouring one side over the other)
- weak suck with feeding, or difficulty swallowing
- not reaching achondroplasia-specific developmental and growth milestones
- poor weight gain

If you think your child has developed any of these symptoms, you should contact the nursing team, [email](mailto:EvelinaEAB@gstt.nhs.uk) EvelinaEAB@gstt.nhs.uk, or go to your nearest emergency department (A&E). If your child is unwell and needs to stay in hospital, you should make sure that their doctor contacts the Evelina London endocrine team.

Treatment for severe FMS

Infants with very severe FMS will benefit from foramen magnum decompression surgery. This is a surgical procedure to widen the foramen magnum to relieve the pressure on the spinal cord. This is done by a neurosurgeon.

Contact us

If you have any immediate concerns about your child, please go to your nearest emergency department (A&E).

If you have any questions or concerns about FMS, please contact the endocrine and bone nurses, [email](mailto:EvelinaEAB@gstt.nhs.uk) EvelinaEAB@gstt.nhs.uk or the team secretary [phone](tel:02071887188) 020 7188 7188 extension 56129, Monday to Friday, 9am to 5pm.

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit [web](http://www.evelinalondon.nhs.uk) www.evelinalondon.nhs.uk

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, [phone](tel:02071883003) 020 7188 3003, Monday to Friday, 10am to 5pm [email](mailto:letstalkmedicines@gstt.nhs.uk) letstalkmedicines@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch, [phone](tel:02071888815) 020 7188 8815 [email](mailto:languagesupport@gstt.nhs.uk) languagesupport@gstt.nhs.uk

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, [phone](tel:111) 111 [web](http://www.111.nhs.uk) www.111.nhs.uk



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