



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for nurseries, schools and colleges

Congenital hyperinsulinism

One of your pupils has a condition called congenital hyperinsulinism, which is present at birth and causes high levels of insulin to be produced. This information sheet from Great Ormond Street Hospital (GOSH) explains about congenital hyperinsulinism and the signs and symptoms of a hypoglycaemic episode where the blood glucose levels fall too low. It also contains guidance for managing hypoglycaemic episodes in the nursery, school or college setting.

If you would like further information about congenital hyperinsulinism or have any questions, please contact the Clinical Nurse Specialists (CNS) for Congenital Hyperinsulinism on 020 7405 9200 ext. 0360 or bleep 1016. You can also email them at cns.hypoglycaemia@gosh.nhs.uk

What is congenital hyperinsulinism?

Congenital hyperinsulinism is characterized by inappropriate and unregulated insulin secretion from the beta-cells of the pancreas. In CHI, the beta-cells release insulin inappropriately all the time and insulin secretion is not regulated by the blood glucose level (as occurs normally).

Normally, the beta-cells release insulin in response to the level of glucose in the blood. Insulin converts the glucose into a form that can be used by the body. If too much glucose is converted, it is stored in the liver and muscles as glycogen. Glycogen can be converted back to glucose to be used when glucose is not available.

In CHI, too much insulin causes the blood glucose level to drop too low. High insulin levels prevent ketone bodies being made. This means that the brain is not only deprived of its most important fuel (glucose), but also ketone bodies which are used as alternative fuels. When the brain has no glucose or ketones to use as fuel then the child is at risk of seizures, loss of consciousness and even brain injury.

How is congenital hyperinsulinism treated?

Treatment aims to keep a child's blood glucose level stable at 3.5mmol/litre to 10mmol/litre. This can be managed by regular high carbohydrate feeds alongside medicines to reduce insulin secretion. Sometimes the management of CHI can be complicated. However, once CHI is stable, a degree of normal life can be achieved. Brain function in CHI can be normal if hypoglycaemia has been diagnosed and treated quickly, but can be very variable depending on the amount of damage caused before diagnosis and treatment.



Medication

Your pupil may need to take their medication at regular intervals throughout the school day as shown in the table below. If the dosage or dose schedule changes as your pupil grows older, we will update this page.

Medicine name	Dose	Dosage times			
		AM	AM	PM	PM
<input type="checkbox"/> Diazoxide					
<input type="checkbox"/> Chlorothiazide					
<input type="checkbox"/> Octreotide					
<input type="checkbox"/> Sirolimus					
<input type="checkbox"/> Other medications					

Food and drink

An important part of treating CHI is to ensure that your pupil has regular and frequent snacks and drinks throughout the school day. These will be provided by your pupil's family and should be carried with them at all times. Please allow them to leave lessons to have a snack or drink if needed. Each day, your pupil should have the following snacks and drinks.

Snack or drink	Times			
	AM	AM	PM	PM

Blood glucose monitoring

Your pupil will also need to check their blood glucose levels at regular intervals throughout the day. Please allow them to leave lessons to do this if needed. Children and young people are given a blood glucose monitor which measures the amount of glucose in the blood. This is done by a small finger prick that will give a single drop of blood to put on a strip. The monitor will display the blood glucose level as a figure measured in mmol/litre.

Blood glucose monitoring should be done at the following times:

AM	AM	PM	PM
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Additional checks may be needed if your pupil is unwell or takes part in energetic activities such as games and school trips. Please liaise with the pupil's family about additional blood glucose monitoring.



Signs and symptoms of hypoglycaemia

A hypoglycaemic episode will occur when blood glucose is less than 3.5mmol/litre. Some children also notice they don't feel right when their blood sugar levels start to go too low.

Common symptoms include:

- Feeling tired or sleepy
- Feeling wobbly or shaky
- Feeling dizzy
- Feeling hungry
- Feeling grumpy or angry
- Having a headache

Your pupil may also show the following symptoms:

If you notice any of these signs, or your pupil is exhibiting unusual behaviour, you should check their blood glucose level immediately and follow the emergency plan below.

Treating a hypoglycaemic episode

Your pupil will carry an emergency Glucogel®/snack with them at all times to deal with a hypoglycaemic episode. If one occurs, inform the family immediately so that, not only are they aware, but they can restock the Glucogel®/snack if required.

- If the blood glucose level is 3.5mmol/litre or lower, recheck using a new finger prick and testing strip
- If the blood glucose level is still 3.5mmol/litre or lower, give them half a tube of Glucogel® and a snack

- Recheck their blood glucose level 10 minutes later using a new finger prick and testing strip
- If their blood glucose level remains at 3.5mmol/litre or lower or they are not responding to the Glucogel® and snack, give them the remaining half of the Glucogel® tube and dial 999 to call an ambulance.

More information about CHI can be found at www.gosh.nhs.uk/medical-information/clinical-specialties/endocrinology-information-for-parents-and-visitors/conditions-we-treat/congenital-hyperinsulinism