

# Managing hypoglycaemic episodes in congenital hyperinsulinism: information for families

Your child has been diagnosed with a condition called congenital hyperinsulinism which causes high levels of insulin to be produced which in turn can cause their blood glucose level to drop too low (hypoglycaemia). The Congenital Hyperinsulinism team at Great Ormond Street Hospital (GOSH) have started treatment with medications but your child may still have hypoglycaemic episodes. This information sheet explains how to monitor your child's blood glucose levels, the symptoms of a hypoglycaemic episode and what to do if you suspect your child is having one.

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. Out of hours, call 020 7405 9200 and ask for the on-call doctor for endocrinology.

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.

The action of insulin causes hyperinsulinaemic hypoglycaemia – that is, the blood glucose level drops 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.

## Monitoring blood glucose levels

You will need to monitor your child's blood glucose levels regularly throughout the day and whenever they are unwell or you suspect they are having a hypoglycaemic episode.

We will provide you with a blood glucose monitor which measures the amount of glucose in the blood. This is done by a small finger or heel 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.

AM	AM	AM	AM
PM	PM	PM	PM

You should also check your child's blood glucose level if they are showing any signs of a hypoglycaemic episode.



## Hypoglycaemic episodes

A hypoglycaemic episode will occur when blood glucose is less than 3.5mmol/litre. Your child may also show signs such as:

- Floppiness
- Shakiness
- Poor feeding
- Sleepiness
- Seizure (fit or convulsion)

## Treating a hypoglycaemic episode

We will give you an individual hypo plan for your child. However, the following is a rough guide.

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

## Glucose products guidance

### Glucose gel tube containing 10g glucose

- Up to six months of age – give  $\frac{1}{3}$  tube = 3.33g
- Six months to two years – give  $\frac{1}{2}$  tube = 5g
- Two to five years – give 1 tube = 10g
- Five years and older – give  $1\frac{1}{2}$  tubes = 15g

### Glucojuice® - 60mls contains 15g glucose

- Two to five years – give 40mls = 10g
- Five years and older – give 60mls = 15g

### Glucose tablets – each tablet contains 4g glucose

- Two to five years – give  $2\frac{1}{2}$  tablets = 10g
- Five years or older – give 4 tablets = 16g

