



Congenital Hyperinsulinism - information for the public

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- As a service we looked at what information we had for patients and their families
- The leaflet used was overwhelming with information as fed back by families



Producing information

- Information is an important part of the patient journey and central to the overall quality of each patient's experience
- It is important that the information can be understood by our patients and aids them to make informed choices about their treatment and care.
- It is also important that the information we produce for other audiences such as visitors and staff is written in a format which is easily understood and assimilated.



Producing information (Cont)

- It is essential that all clinical information given to patients is up-to-date and accurate
- It is important that the information we provide to patients and their families is clearly written, contains accurate and up-to-date content and can be understood by the intended target audience



Good information can:

- Give patients confidence so their overall experience as a patient is improved.
- Remind patients what their doctor, nurse or other health professional told them.
- Allow people to make informed decisions – it gives people time to go away, read the information and think about the issues involved.
- Involve patients and their carers in their treatment and condition.



Communication must be:

- Clear – so it can be understood.
- Straightforward – Using fewer words and keeping to the necessary information.
- Modern – using everyday language.
- Accessible – Available to as many people as possible. It needs to be up-to-date, not contain jargon and be given to the patient at the appropriate time.
- Honest – Information should be based on current evidence.
- Respectful – Sensitive to cultural needs and all people, avoiding stereotypes.



- With all this in mind we decided to redesign our information leaflets
- With the help of a neuroscience student (specialist subject science communication and the media) at the university of Manchester, we also produced 3 videos on CHI

Congenital Hyperinsulinism Patient Information Booklet

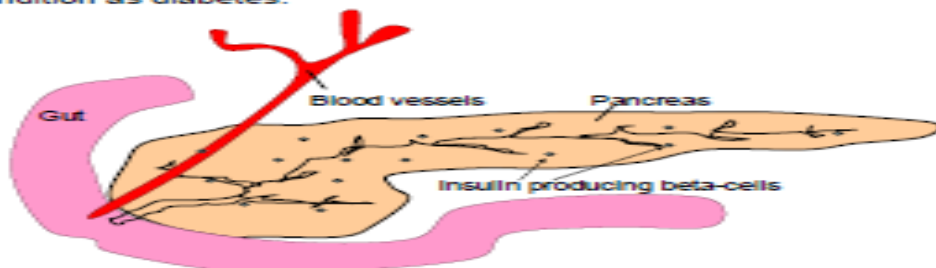
This booklet is aimed to provide you with both some basic and more detailed information on Congenital Hyperinsulinism (CHI). We hope that by reading this, we will help you understand how this very complex condition occurs, how we diagnose it and what the treatment involves. It will in no way answer all your questions about CHI, so please feel free to ask any member of our Northern Congenital Hyperinsulinism Service (NORCHI) team any questions you might have about CHI, even after you have read it.

Why is my child here? What is NORCHI?

CHI is a rare condition that can have very profound effects on the development of your child. For this reason, the National Commissioning Group (NCG) commissioned two specialist centres in England to treat this condition (Great Ormond Street Hospital and NORCHI). NORCHI is a joint service based between two of the largest specialist children's hospitals in the North of England, i.e. the Royal Manchester Children's Hospital and Alder Hey Children's Hospital, Liverpool. For this reason, you and your child have been referred to us, to provide your child with the most up to date diagnostic facilities and initiate the best treatment currently available.

What is CHI?

Congenital hyperinsulinism (CHI) is a disorder that causes dangerously low blood sugars in newborn babies and children. This is caused by the uncontrolled release of a hormone in the body called insulin. Insulin is produced by beta-cells located in an organ called the pancreas. It is however very important to note that although CHI involves insulin, it is not the same condition as diabetes.



Since being first recognised in the mid 1930s, CHI has been given many different names. Terms such as nesidioblastosis, idiopathic hypoglycaemia of infancy, leucine-sensitive hypoglycaemia and persistent hyperinsulinaemic hypoglycaemia of infancy (PHHI) have all been used to describe this condition in the past.

Worldwide figures suggest that CHI occurs in approximately 1 in 25,000 to 50,000 of children born, with higher rates among specific ethnic populations. This makes CHI a very rare condition. Of those with CHI, more than half are diagnosed in the newborn period, with the remainder diagnosed in the first three years of life.

Why is diagnosing CHI important?

Severe low blood sugars can cause many problems. Most commonly, they cause tiredness and reduced feeding. More importantly, are the effects of low blood sugars on the brain. Sugar is a form of fuel for the brain. In normal children, when low blood sugars occur, the body is able to break down fats to form a different type of brain fuel called ketones. This unfortunately cannot happen in CHI, so the brain is starved when low blood sugars occur



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What is Congenital Hyperinsulinism?

Congenital Hyperinsulinism

Patient/Carer Information Booklet 1

How do low blood sugars occur?

Congenital Hyperinsulinism (CHI)

Patient/Carer Information Booklet 2

What are the types

Congenital Hyperinsulinism (CHI)

Patient/Carer Information Booklet 3





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Genes and CHI

Congenital Hyperinsulinism (CHI)

Patient/Carer Information Booklet 4

CHI diagnosis and treatment

Congenital Hyperinsulinism (CHI)

Patient/Carer Information Booklet 5

Central lines, feeding and beyond

Congenital Hyperinsulinism (CHI)

Patient/Carer Information Booklet 6





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Surgery in CHI

Congenital Hyperinsulinism (CHI)

Patient/Carer Information Booklet 7





- Introduction to the genetics of CHI -
<https://www.youtube.com/watch?v=qN3JdWW0L-I>
- Focal CHI -
<https://www.youtube.com/watch?v=h-5XsG5ICKQ>
- Effects of hypoglycaemia in CHI -
<https://www.youtube.com/watch?v=rT1y2sCGTPc>



- Parents were consulted during the composition stage of production
- We have trialed the booklets with families and have received very positive feedback
- No information overload as information is divided into booklets and given as needed
- Videos were produced in close consultation with parents of children with HI
- We are planning to do further videos possibly on drugs used to treat HI and one on surgery for HI

Thank-you

