**Your child's just been diagnosed with HFI. Next steps:**

Whilst it's always a shock to receive a diagnosis of a rare disorder for your baby or child, as inherited conditions go, HFI is relatively straightforward to manage. Our charity is here to support you every step of the way.

You will probably have a thousand questions, and are probably feeling very overwhelmed right now - which is completely understandable and normal when you receive a genetic diagnosis.

Once your child has a HFI diagnosis, we feel that it is important to make sure that your child is seen by a specialist metabolic paediatrician. If you have not been referred, we can tell you where your nearest specialist paediatric centre is.

There are many questions that you will want to be asking the paediatrician, and here are some that are important:

**Medicines:**

Paracetamol. Children's paracetamol syrups in most countries contain sugars that are not safe, so ask your paediatrician to prescribe a safe version. Even infant paracetamol labelled "Sugar free" will contain unsafe sweetening such as sorbitol or maltitol liquid. These are **NOT SAFE** for a child with HFI. In England, paracetamol suppositories are available. Much better to have these in the cupboard ready rather than panic when you have an unwell baby! Always consult with a paediatrician or pharmacist about any medication.

Ibuprofen. All ibuprofen liquid infant formulations are **NOT SAFE** for a child with HFI. They contain sorbitol, sucrose, or high-fructose corn syrup. Ask your paediatrician or pharmacist about any safe alternative.

Antibiotics. Most oral liquid antibiotics are formulated to taste good for children, meaning they are heavily loaded with sugar as fructose, sucrose or sorbitol. Always check with your paediatrician or pharmacist for safety to use with an HFI child.

The same problem of unsafe sugars will present for most teething remedies or any oral medications that your child may require throughout childhood.

Vaccinations. The routine childhood vaccination schedule in the UK is HFI safe, **except** for the rotavirus vaccine. We are working with a metabolic specialist to try to get Rotavirus vaccine companies to change their formulation to be safe for HFI. Until this happens, avoid your little one having the rotavirus vaccine.

**Diet:**

A safe HFI diet means eliminating fructose, sucrose and sorbitol from the diet. Some infant milks have sucrose in them! It's important to check the label of everything that your child will eat or drink. Even some child toothpastes contain sorbitol! If you haven't already been referred, ask to see a specialist paediatric metabolic dietician. They will be able to talk through a safe diet with you. Your child may need Vitamin C supplements. Ask your dietician what they recommend. Write a list of things that you want to ask a dietician, and go through your list with them.

Ask for a plan at your first appointment with the paediatrician and dietician about what to do if your child is accidentally exposed to fructose, sucrose or sorbitol.

Keep a note of phone numbers for the metabolic team in case you need to call them, or take your child to hospital.

Please know that there are absolutely ZERO 'silly' questions, and we would much rather you emailed and asked instead of sitting and worrying. Please feel free to email us at the support charity or join the WhatApp support group that we have. Carol, Bill or Dannie at HFI Support are always happy to answer as many questions as you have.

If your child has already sustained any liver damage when they are diagnosed, although it will take a long time, with a safe diet their liver should recover.

We have a downloadable information sheet for giving child carers, nurseries and schools basic advice about how to manage a child with HFI. You'll find it in the Information, resources section.

**Medical alert information:**

Consider getting an alert tag or band that will always provide information about your child's HFI should they become ill or have an accident and you are unable to advocate for them. You'll find a link to Safe and Snappy, which provide such tags and bands, in our resources section.

Suggestions for the information provided on an alert band via a QR code might include:

**Contact names** and phone numbers of parent/carer
**Medications** list (if anything prescribed)
**Contact numbers** for your specialist paediatric nurse and dietician and oncall bleep numbers if you have been given them

**What to do in an emergency section:**

Do NOT give oral medication containing fructose, sucrose or sorbitol (including liquid paracetamol and liquid antihistamine)
Contact emergency contacts immediately

Add "**Hereditary Fructose Intolerance (Metabolic Disorder)"** into the "Medical Conditions" section *and* under the 'allergies' section*

*Although HFI is not an allergy, by using this section it is more likely to alert people to the potential seriousness of the condition.

Consider an explanation such as:

(Child's name).....'s metabolic condition means he/she cannot consume any food or drink containing fructose, sucrose or sorbitol, no fruit or vegetables or any meat with added sweeteners or 'natural flavourings',

For an "Other notes" section we suggest something like:

Hereditary Fructose Intolerance (HFI) is a rare metabolic condition. .(Name)... must not consume food, drink or medicines containing fructose, sucrose or sorbitol otherwise he/she is at risk of hypoglycaemia, liver and kidney damage, seizures, coma or death.

(Name)...'s specialists are the paediatric metabolic team at ... (name hospital).. who are contactable during working hours on: (phone number and/or bleep number)

With a safe diet, children with HFI will absolutely thrive. You may need to be a bit more creative at times, to provide the 'normal childhood experiences' like birthday cakes(!) and going on trips away from home where food is more unknown, but it becomes the norm. You'll become very good at reading labels, being creative in the kitchen and packing a good packed lunch with short notice!