



It's all in the genes

Genetic haemochromatosis, which causes the body to absorb too much iron, is a common genetic disorder so why is awareness so low?

BY JANE YETTRAM

YOU'VE PROBABLY heard of anaemia, a lack of iron leading to low levels of red blood cells. But genetic haemochromatosis (GH), caused by too much iron, is far less well known – even though it affects almost 1.2 million people in the UK.

This excess iron – stored in the liver, heart, pancreas and joints – is toxic. Early symptoms include fatigue, aching joints and stomach pain, but iron can build up silently with no symptoms at all – and, left untreated, can lead to liver cancer or heart failure.

That's why diagnosis – through a simple blood test checking for the genes that carry GH – is important. However, "NHS services are patchy,"

says Neil McClements, Chief Executive of Haemochromatosis UK, a charity supporting those affected. "It's a postcode lottery."

There's no cure for GH, but the treatment – venesection (taking out blood to remove excess iron) – is simple and effective. "Yet many people don't realise they have the condition until it's too late," says Neil. "Early diagnosis saves lives."

A FIGHT FOR DIAGNOSIS

For 50-year-old John* diagnosis only came through his own persistence. He had assumed his chronic fatigue was due to his busy life. "I stopped drinking, went to bed earlier, but still felt awful," he says.

Blood tests showed his iron levels were high, but his doctor said "that

shouldn't be a bad thing". Only at John's insistence was he given a genetic test – which revealed GH.

For nine months, John had weekly venesections. Then, with his consultant away on holiday, he saw a different doctor who asked, "where's your heart scan?". "I didn't know I needed one," says John, who discovered that heart and liver scans are recommended to check for organ damage.

John is stunned by the ignorance surrounding the condition. "People have been dying of GH-related illness for years. If I hadn't persisted, I could have been one of those statistic deaths."

● For support and information, visit haemochromatosis.org.uk

CHECK UP
Blood tests measuring iron levels are included as part of a Benenden Health Assessment. To book, call 0800 652 2209 or visit benenden.co.uk/membercheck. Discounts are available for Benenden Health members.

* NAME CHANGED