What is severe insulin resistance?

Severe insulin resistance and lipodystrophy are rare metabolic disorders. They occur when the body does not use the insulin it produces properly.

Insulin is a hormone (a chemical signal that travels in the bloodstream) made by the pancreas. It controls how the body uses sugars and fats and is essential for life. Its absence is the underlying problem in type 1 diabetes. However, from person to person there are significant differences in how sensitive the tissues of the body are to insulin. In other words, in some people a very small amount of insulin produces a large change in the blood levels of glucose and fats (these people are said to be very insulin sensitive), while in others much larger amounts are required to produce the same change (these people are said to be insulin resistant). Those with severe insulin resistance are those whose bodies respond least well to insulin. Although many with severe insulin resistance do go onto develop diabetes, severe insulin resistance is NOT the same as diabetes: as long as the pancreas can produce enough insulin to overcome the insulin resistance diabetes does not develop. However even before diabetes appears, insulin levels in the body may be extremely high, and this can produce a range of different problems in its own right.

Rarely, people are born with severe insulin resistance and remain severely insulin resistant throughout their lives. Far more frequently insulin resistance develops only at puberty or in later life, while in some people it is only a temporary condition caused by other situations or illnesses. Most commonly a tendency towards insulin resistance is inherited, but only in the presence of environmental or lifestyle factors does it become a problem.

Consequences of severe insulin resistance include development of metabolic problems, including diabetes, elevated levels of fats in the blood (triglycerides and cholesterol), fatty liver disease, pancreatitis and polycystic ovary syndrome. In rare patients with infantile disease (Donohue and Rabson Mendenhall Syndromes) there is a combination of severe metabolic and growth defects.

Patient stories

The National Severe Insulin Resistance Service (NSIRS) was commissioned by NHS England in 2011 to provide diagnostic, therapeutic and educational support for adults and children with known or suspected syndromes of severe insulin resistance (SIR). Clinical Lead Dr Anna Stears and Diabetes Specialist Nurse Charlotte Jenkins Liu discuss the service and
present some case studies illustrating the work it does.