THE UNIVERSITY OF CHICAGO MEDICINE
Kovler Diabetes Center

Monogenic Diabetes FAQs

Frequently Asked Questions About Neonatal Diabetes

What is neonatal diabetes?

Neonatal diabetes can be permanent (permanent neonatal diabetes mellitus, PNDM) or transient (transient neonatal diabetes mellitus, TNDM). In PNDM, the diabetes requires treatment for the person's entire life. In TNDM, the diabetes may go away and no longer require treatment after the first few months of life. However, the diabetes will often return later in life. It is very important to have genetic testing done to help guide treatment, prognosis and monitoring for diabetes recurrence.

How many people have neonatal diabetes?

Neonatal diabetes is very rare. About 1 in 100,000 babies born have neonatal diabetes.

Who should be tested for neonatal diabetes?

Anyone diagnosed with diabetes at 12 months of age or younger should be tested for monogenic neonatal diabetes.

If my child has neonatal diabetes, can he/she be treated with pills?

There is a possibility that your child can transition from insulin injections to pills (sulfonylureas). However, this change is only possible with certain types of neonatal diabetes (such as those caused by mutations in the KCNJ11 or ABCC8 genes). Any treatment changes and the best treatment for your child should be decided by his or her physician.

Frequently Asked Questions About MODY

What is MODY?

Maturity-onset diabetes of the young, or MODY, is a form of monogenic diabetes that is caused by mutations in a number of different genes. Each different mutated gene causes a slightly different type of diabetes.

MODY is typically diagnosed in late childhood, adolescence, or early adulthood. However, it has been known to develop in adults as late as their 50s. Many people with MODY are misdiagnosed as having type 1 or type 2 diabetes.

How many people have MODY?

It is believed that up to 2 percent of all diabetes cases are due to MODY.

Who should be tested for MODY?

- A diabetes patient who is part of a family with three or more consecutive generations affected by diabetes
- A diabetes patient with stable, mildly elevated blood sugars, often found incidentally during a routine check-up
- A "type 1" diabetes patient who has negative blood testing for autoantibodies, typically done at the time of diabetes diagnosis (antibodies typically tested include one or more of the following: GAD65, islet cell or ICA, IA-2, insulin, ZnT8)
- A "type 1" diabetes patient who generates a significant amount of insulin years beyond diagnosis (detectable blood levels of c-peptide, proinsulin, and/or insulin)
- A "type 2" diabetes patient who is normal weight or not significantly overweight and shows no signs of insulin resistance
- Diabetes paired with pancreatic insufficiency
- Individual or family history of diabetes paired with developmental kidney disease or abnormalities of the kidney (especially cysts)