

## **PARENT INFORMATION for Positive newborn screening results for MCAD (Medium Chain Acyl CoA Dehydrogenase Deficiency)**

When your baby was born a small sample of blood was taken from your baby's heel to test for certain diseases. These diseases usually cannot be found simply by looking at your baby, so that is why the blood test is so important.

The results of your baby's screening test were positive for a disorder called MCAD. It is important to remember this is only a screening test. A new blood sample will be collected from your baby and a new test will be done to help find out if your baby has MCAD or not.

### **What does a positive screen mean?**

A positive screen means that your baby needs a new blood test to check for MCAD. A small percent of all babies screened are identified as positive on screening. Some are later found not to have the disorder. This is just a screening test and further testing must be done to determine if your child has MCAD or not. Keep in mind that the new test could show that your baby does not have MCAD.

### **What is the next step?**

It is important to follow your baby's doctor's instructions for getting a new blood sample for further testing. The doctor may give you steps that you can take to reduce the risks of problems occurring if your baby has MCAD. Since MCAD is a rare metabolic disease, your doctor may consult with or refer you to a pediatric metabolic specialist.

### **What exactly is MCAD?**

MCAD is a disorder that causes problems with breaking down the fat from

food. People with MCAD lack the enzyme necessary to process some fats into sugars. Problems can occur during periods of fasting, such as when too much time occurs between breast or bottle-feeding. Problems can also occur during periods of illness when there is vomiting or diarrhea. At these times, the baby's blood sugars can drop to dangerous levels. This can lead to seizures, coma, and even death. If the baby survives the crisis, there may be severe developmental disabilities.

Finding out early if your baby has MCAD means you and your baby's doctor can take steps to prevent this.

### **What should I do?**

**The most important thing you can do is to be sure your baby does not go without feedings for more than 4 hours.** Usually newborns will need to be fed more frequently than this, so you should not worry as long as your baby is fed at least every 4 hours.

**Make sure that your baby has a new blood sample collected and tested as soon as possible.**

**Also, call your baby's doctor immediately, if your baby shows any signs of illness such as fever, vomiting, or diarrhea.** Your baby's doctor may prescribe a metabolic supplement called "carnitine". If so, it will be important to follow the doctor's instructions.

You have probably already done this, but now is also a good time to be sure your newborn is covered by your health insurance provider. Most health insurance covers all or part of the medical treatment needed for MCAD.

For more information, talk with your baby's doctor. You can contact the Nebraska Newborn Screening Program at (402) 471-0374 for information on Pediatric Metabolic Specialists available in Nebraska.