



# Short Chain Acyl CoA Dehydrogenase Deficiency (SCADD)

### What is newborn screening?

Newborn screening (NBS) is done soon after birth to check for health conditions that can be hidden at birth. To do the screening, a nurse takes a few drops of blood from your baby's heel.



Your baby's newborn screen flagged for a condition called short-chain acyl-CoA dehydrogenase deficiency (SCADD). Just because the newborn screen was flagged for SCADD, it does not mean that your child has a diagnosis of SCADD.

The NBS is a screening test---it determines whether a baby has a risk of having a condition. Sometimes, an out of range result can happen for reasons other than having the disorder, such as:

- The sample was too small
- The sample was collected too early
- The sample was collected too close to a feeding
- The baby was born too early or had a low birth weight

# What Short Chain Acyl CoA Dehydrogenase Deficiency (SCADD)?

SCADD is considered a fatty acid oxidation condition because it **was** thought that people who have this disorder could have a hard time changing some of the fats that they eat into energy for the body.

#### **KEY POINTS:**

- You have just heard that your baby might have SCADD. Please understand that the newborn screening is just that---a screening test. A diagnosis has not been made.
- Most babies who have a newborn screen that flagged for SCADD are healthy.
- Most babies who have had additional diagnostic testing did not go on to be diagnosed with SCADD.
- SCADD is a low risk condition. It is rare for people with SCADD to have any symptoms.
- Children who are diagnosed with SCADD can have healthy growth and development with no treatment or diet changes.
- Please discuss with your baby's doctor if you would like to have diagnostic testing to determine if your baby has SCADD.

We now know that people with SCADD are very unlikely to have any medical symptoms related to this diagnosis. You may find old information on the internet that discusses diet changes or other treatments for SCADD. However, there are currently no recommended dietary changes or treatments for people who are diagnosed with SCADD following a newborn screen.

#### CONNECTICUT NEWBORN DIAGNOSIS AND TREATMENT NETWORK • OCTOBER 2020 • PAGE 2

### What additional testing would be needed to know if my baby has SCADD?

Follow up diagnostic testing can be done to find out if your child has SCADD.

This testing would include a blood test and a urine test. For some babies, a genetic test would also be needed. Most babies who go on to have diagnostic testing do not get a diagnosis of SCADD.

# Can we decide if we want to have the extra diagnostic testing?

Further testing would be needed to learn if your baby actually has SCADD. However, since a diagnosis of SCADD would not change medical care of your child, you can decide if you would like to have further testing, or not.



# What happens next?

We have a genetic counselor on staff if you would like to talk more about SCADD and the option to have diagnostic testing or to not have diagnostic testing. Parents and/or physicians can contact 860-837-7870 to schedule an appointment to speak with a genetic counselor.

If you decided to have diagnostic testing, we can help to coordinate this testing. You, or your baby's doctor, can call us at 860-837-7870.

If you decide not to have the diagnostic testing at this time, please let us know your decision by returning the attached document to your baby's doctor, so that we know we can close the report with the Department of Public Health Newborn Screening Program.

# What if I still have questions?

We understand that this can be an overwhelming and emotional process. Many families have questions and concerns. The Connecticut Newborn Diagnosis and Treatment Network (the Network) is available to put you in touch with the best resource. To reach the Network, you can call 860-837-7870, Monday-Friday, 8:30am-4:30pm.

This fact sheet was written for information purposes only. It should not replace medical advice, diagnosis or treatment.

