

# **PARENT FACT SHEET**

## **DISORDER**

### **Biotinidase Deficiency (BIO)**

#### **CAUSE**

BIO affects the way a person's body uses the vitamin, biotin. Biotin is an important vitamin that helps enzymes, called carboxylases, make certain fats and carbohydrates and help break down proteins. A child with BIO cannot use biotin when it is still bound to food. Biotin can only be used in its free form and is essential for proper growth and development.

#### **IF NOT TREATED**

Most infants with BIO appear normal at birth, but develop serious symptoms after the first few weeks or months of life. Low biotin levels can cause seizures, developmental delay, hearing loss, vision problems, and other serious and sometimes life-threatening illnesses.

#### **TREATMENT OPTIONS**

Your child will need to be under the care of a metabolic specialist. Treatment is needed throughout life.

- Biotin supplements can be taken orally and come in many forms – capsules, tablets, and liquids. Biotin supplements are safe and non-toxic.
- Your child's metabolic specialist will determine the proper dose that should be taken.
- A prescription is required for biotin supplements.
- Regular blood work will be required to monitor your child's progress in the event any changes in treatment need to be made.

#### **IF TREATED**

Because newborn screening can detect virtually all cases of BIO, treatment can be started very quickly. If your child begins treatment before showing any symptoms, biotin supplements can prevent all symptoms from occurring. If your child is already showing symptoms, most of those symptoms will improve upon being treated. Biotin therapy will not reverse brain damage that occurs before treatment is started, but it will prevent further damage from occurring. However, vision and hearing loss may not respond to biotin treatment, depending on the time between the beginning of symptoms and the start of treatment. Some children achieve rapid developmental milestones while others show continued developmental delays.