



July 2, 2019

Dear Family,

Like all Alaska babies, your infant born on \_\_\_\_\_ had a test called the Newborn Bloodspot Screening. The test showed that your baby has two copies of a gene called the Arctic Variant of Carnitine Palmitoyl Transferase-1 (CPT1A).

Most babies with two copies of this gene never have any problems. Your baby does not need any medications, or a special diet. The only time that having two copies of this gene could cause problems is when your baby is sick, has a fever, or for some other reason can't eat or drink as much as they usually do. At such times, it could be hard for your baby to keep their energy up, which could cause them to be very sleepy, and lose interest in eating. Your baby may also get shaky, or jittery.

*When your baby is sick* it is important to encourage them to eat and drink plenty of fluids with calories, such as breast milk, formula, or Pedialyte. If your baby won't eat, or starts acting unusually sleepy or jittery, it is important that you contact your baby's health care provider right away.

Enclosed you will find a DVD and card that were made especially for families caring for infants and children with CPT1A Arctic Variant. This DVD was developed as a joint project between the Alaska Native Medical Center, Norton Sound Health Corporation, and the State of Alaska Department of Health and Social Services.

Please keep this letter and card to take with you to the local clinic/hospital whenever your child is sick or needs care.

If you have any questions about the DVD or CPT1A Arctic Variant, please contact your local health care provider.

Sincerely,

A handwritten signature in black ink, appearing to read "Matthew Hirschfeld".

Alaska Newborn Screening Program  
State of Alaska, DHSS, DPH, WCFH

Matthew Hirschfeld, MD, PhD  
Medical Director  
Maternal Child Health Services,  
Alaska Native Medical Center