

Attachment 5
Instructions and State Form

Instructions

For this study, the children of interest were diagnosed with a screened metabolic disorder identified outside of the newborn screening system (i.e. clinically) or identified through newborn blood spot screening but with a delay in diagnosis or initiation of treatment. These children must have been born in the United States, Puerto Rico, or the Virgin Islands and have a clinical diagnosis of classical phenylketonuria, primary congenital hypothyroidism, galactosemia (any type if law is not restrictive), maple syrup urine disease, homocystinuria, biotinidase deficiency, classical congenital adrenal hyperplasia (saltwasting or simple virilizing), or sickle cell disease if the states where they were born screened for these disorders at the time of the child's birth.

- Please use the following two forms (labeled "State Form" and "Case Report Form") to assist with the collection of data.
- Please prepare a separate Case Report Form for each case. Copy the blank form as necessary.
- Please fill out the State Form and return even if you have no cases to report.
- Please return the forms (State and Case Report) using the enclosed prepaid envelope, or send to the following address:

L. Omar Henderson, Ph.D.
Centers for Disease Control and Prevention
4770 Buford Highway, N.E., Mailstop F-43
Atlanta, GA 30341-3724
(770) 488-7972 (phone)
(770) 488-4255 (fax)

Thanks for your help!

State Form

State: XX (CDC enters state name)

Please check appropriate line:

_____ **We are not aware of any cases of delayed diagnosis (missed cases) between the years 1984 and 2004.**

_____ **We have _____ (#) of cases of delayed diagnosis (missed cases) to report.
(please use a separate Case Report Form for each reported case)**

Please return this page even if you have no cases to report

Public reporting burden of this collection of information is estimated to average 3 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS-D73, Atlanta, Georgia 30333; ATTN: PRA (0920-0641).