

Attachment H--Newborn Screening PROGRAM data collection instrument

Form Approved
 OMB No. 0920-0879
 Expiration Date: 03/31/2014

Thank you for providing input as part of our effort to demonstrate the capacity and impact of state newborn screening programs. For each condition listed in the tables that follow please provide for your state: the first year of state-wide screening and the number of confirmed cases in 2009, 2010, and 2011.

Where the number of cases for a condition exceeds the largest value in the drop down menu, note the year and actual number of cases in the corresponding comments section.

1. State

State

2. Organic Acid Conditions

	Year Started Statewide Screening	# Confirmed Cases, 2009	# Confirmed Cases, 2010	# Confirmed Cases, 2011
PROP--Propionic acidemia				
MUT--Methylmalonic acidemia (methylmalonyl-CoA mutase)				
Cbl A,B--Methylmalonic acidemia (cobalamin disorders)				
IVA--Isovaleric acidemia				
3-MCC--3-Methylcrotonyl-CoA carboxylase deficiency				
HMG--3-Hydroxy-3-methylglutaric aciduria				
MCD--Holocarboxylase synthase deficiency				
βKT--β-Ketothiolase deficiency				
GA1--Glutaric acidemia type I				

Comments about Organic Acid Conditions. Be sure to note here the year and # of cases for any condition where the # confirmed cases exceeds the drop down maximum.

Public reporting burden of this collection of information is estimated to average 38 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 Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-0879).

3. Fatty Acid Oxidation Conditions

	Year Started Statewide Screening	# Confirmed Cases, 2009	# Confirmed Cases, 2010	# Confirmed Cases, 2011
CUD--Carnitine uptake defect/carnitine transport defect				
MCAD--Medium-chain acyl-CoA dehydrogenase deficiency				
VLCAD--Very long-chain acyl-CoA dehydrogenase deficiency				
LCHAD--Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency				
TFP--Trifunctional protein deficiency				

Comments about Fatty Acid Oxidation Conditions. Be sure to note here the year and # of cases for any condition where the # confirmed cases exceeds the drop down maximum.

4. Amino Acid Conditions

	Year Started Statewide Screening	# Confirmed Cases, 2009	# Confirmed Cases, 2010	# Confirmed Cases, 2011
ASA--Argininosuccinic aciduria				
CIT--Citrullinemia, type I				
MSUD--Maple syrup urine disease				
HCY--Homocystinuria				
PKU--Classic phenylketonuria				
TYR I--Tyrosinemia, type I				

Comments about Amino Acid Conditions. Be sure to note here the year and # of cases for any condition where the # confirmed cases exceeds the drop down maximum.

5. Endocrine Disorders

	Year Started Statewide Screening	# Confirmed Cases, 2009	# Confirmed Cases, 2010	# Confirmed Cases, 2011
CH--Primary congenital hypothyroidism				
CAH--Congenital adrenal hyperplasia				

Comments about Endocrine Disorders. Be sure to note here the year and # of cases for any condition where the # confirmed cases exceeds the drop down maximum.

6. Hemoglobin Disorders

	Year Started Statewide Screening	# Confirmed Cases, 2009	# Confirmed Cases, 2010	# Confirmed Cases, 2011
Hb SS--S,S disease (Sickle cell anemia)				
Hb S/βTh--S, βeta-thalassemia				
Hb S/C--S,C disease				

Comments about Hemoglobin Disorders. Be sure to note here the year and # of cases for any condition where the # confirmed cases exceeds the drop down maximum.

7. Other Disorders

	Year Started Statewide Screening	# Confirmed Cases, 2009	# Confirmed Cases, 2010	# Confirmed Cases, 2011
BIOT--Biotinidase deficiency				
CCHD--Critical congenital heart disease				
CF--Cystic fibrosis				
GALT--Classic galactosemia				
HEAR--Hearing loss				
SCID--Severe combined immunodeficiencies				

Comments about Other Disorders. Be sure to note here the year and # of cases for any condition where the # confirmed cases exceeds the drop down maximum.

<<<<<END OF DATA COLLECTION>>>>