

Attachment I--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

* 2. Organic Acid Conditions

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

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).

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*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	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
MCAD--Medium-chain acyl-CoA dehydrogenase deficiency	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
VLCAD--Very long-chain acyl-CoA dehydrogenase deficiency	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
LCHAD--Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
TFP--Trifunctional protein deficiency	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
CIT--Citrullinemia, type I	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
MSUD--Maple syrup urine disease	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
HCY--Homocystinuria	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
PKU--Classic phenylketonuria	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
TYR I--Tyrosinemia, type I	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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.

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*5. Endocrine Disorders

	Year Started Statewide Screening	# Confirmed Cases, 2009	# Confirmed Cases, 2010	# Confirmed Cases, 2011
CH--Primary congenital hypothyroidism	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
CAH--Congenital adrenal hyperplasia	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Hb S/ β Th--S, beta-thalassemia	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Hb S/C--S,C disease	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
CCHD--Critical congenital heart disease	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
CF--Cystic fibrosis	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
GALT--Classic galactosemia	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
HEAR--Hearing loss	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
SCID--Severe combined immunodeficiencies	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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.