**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-methyglutaric aciduria** |  |  |  |  |
| **MCD--Holocarboxylase synthase deficiency** |  |  |  |  |
| **ßKT--ß-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/ßTh--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 immunodeficiences** |  |  |  |  |

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>>>>