Attachment C –Surveillance Summaries

National Disease Surveillance Program - I. Case Reports OMB No. 0920-0009

Creutzfeldt-Jakob Disease Surveillance

Creutzfeldt-Jakob disease (CJD) is an invariably fatal neurodegenerative disease that occurs at about one case per million population per year. About 10% of CJD deaths occur in patients <55 years of age. Since 1996, a new variant form of CJD (vCJD) has been reported to occur among unusually young patients primarily in the United Kingdom but also other European countries. Most vCJD patients died at <55 years of age. Strong laboratory and epidemiologic evidence indicate that vCJD is causally linked with bovine spongiform encephalopathy (BSE). BSE is a disease in cattle that was first recognized in the United Kingdom in 1986 but has since been identified in many other European countries, Canada, Japan, Israel, and the United States. The first vCJD case in the United States was reported in a long-term U.S. resident who was born and raised in the United Kingdom during the height of the BSE epidemic there. CDC monitors the occurrence of CJD and vCJD in the United States by employing several CJD surveillance mechanisms. One of these mechanisms focuses on the striking difference in age distribution of CJD and vCJD cases and involves investigation of CJD decedents <55 years of age.

However, because the patients are deceased, IRB has not raised human subject concerns. HIPAA allows collection of data for public health surveillance purposes.

The occurrence of these diseases has been shown to differ among various racial groups, and certain racial/ethnic groups may be more at risk for certain disease complications. It is therefore important to collect race/ethnicity information.

Data collection methodology: Surveillance forms are completed by the state and submitted to CDC.

Kawasaki Syndrome (CDC 55.54)

Kawasaki syndrome is an acute febrile vasculitis of unknown etiology that primarily affects children <5 years of age. It is a leading cause of acquired heart disease of children in the United States. Kawasaki syndrome occurs in a winter-spring seasonality, male predominance, and occasional community-wide outbreaks. During non-outbreak years, the incidence of Kawasaki syndrome could range from 9-19 cases per 100,000 children <5 years of age. Kawasaki syndrome can result into various types of complications. Coronary artery ectasia, the most serious complication of Kawasaki syndrome, can occur in up to 20% of untreated patients. The mainstay treatment for Kawasaki syndrome is administration of intravenous immunoglobulin and long-term aspirin. The use of intravenous immunoglobulin within 10 days of Kawasaki syndrome onset has been shown to reduce the severity of the illness and the occurrence of cardiac complications.

Identifying information is not collected. IRB approvals are not required for these data collections. State/local health departments submit surveillance forms to CDC without patient name. An assigned patient code number or other available data may be used by the state to identify the patient if necessary.

The occurrence of these diseases has been shown to differ among various racial groups, and certain racial/ethnic groups may be more at risk for certain disease complications. It is therefore important to collect race/ethnicity information. Much of our surveillance data are compared to hospital discharge data, death certificate data, and other data sources where only one race can be listed. For comparison purposes, it is best to allow for only one race to be selected; however, the “other” box may be used as an option for patients where more than one race cannot be specified.

Data collection methodology: Surveillance forms are completed by the state and submitted to CDC.

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1Reye Syndrome Case Surveillance Report (CDC 55.8)

Reye syndrome is an acute illness characterized by encephalopathy and fatty degeneration of the liver, and it occurs almost exclusively in children. In about one-third of patients, Reye syndrome results into death or severe, long-term neurologic complications. The occurrence of Reye syndrome is associated with the use of aspirin during viral infections such as influenza-like illness and varicella. Beginning in 1980, CDC cautioned physicians and parents not to use aspirin during these viral diseases. Labeling of aspirin-containing medications was required since 1986. As a result of these preventive measures, there has been a dramatic decline in the occurrence of Reye syndrome in the United States. However, rare preventable cases of Reye syndrome

continue to occur. Continuous surveillance of Reye syndrome is required to monitor a possible resurgence of Reye syndrome with an increased use of aspirin or other new medications that are being introduced into the U.S. market.

Identifying information is not collected. IRB approvals are not required for these data collections. State/local health departments submit surveillance forms to CDC without patient name. An assigned patient code number or other available data may be used by the state to identify the patient if necessary.

The occurrence of these diseases has been shown to differ among various racial groups, and certain racial/ethnic groups may be more at risk for certain disease complications. It is therefore important to collect race/ethnicity information.

Data collection methodology: Surveillance forms are completed by the state and submitted to CDC.

Acute Flaccid Myelitis

Acute Flaccid Myelitis (AFM) is a generally uncommon neurological syndrome characterized by focal limb weakness and abnormalities of the spinal cord gray matter on magnetic resonance imaging (MRI). AFM is a form of acute flaccid paralysis (AFP), which can have numerous varying etiologies. Prior to successful vaccination efforts, the most common cause of AFM worldwide was poliovirus; however, AFM may be caused by numerous other viruses including West Nile virus, herpesviruses, and other viruses including non-polio enteroviruses. In 2014, an apparent increase in AFM cases was detected in the United States, with over 100 cases reported over a five month period. However, an etiology for this outbreak was not identified. Surveillance for AFM is critical to further understand the potential etiologies of this syndrome and ensure that imported and indigenously acquired poliomyelitis cases are detected in the United States.

Identifying information is not collected. IRB approvals are not required for these data collections. State/local health departments submit surveillance forms to CDC without patient name. An assigned patient code number or other available data may be used by the state to identify the patient if necessary.

As there may be numerous potential etiologies, the occurrence of AFM may differ among various racial groups, and certain racial/ethnic groups may be more at risk for certain disease complications. It is therefore important to collect race/ethnicity information.

Data collection methodology: Surveillance forms are completed by the state and submitted to CDC.