

ICD-10 Code PAG Action Plan

April 12, 2024

What is an ICD-10 Code?

An ICD-10 code is an internationally accepted diagnostic code used to describe and track a disease within a population. ICD codes have been maintained by the World Health Organization (WHO) since 1948. The U.S. has been using the 10th Revision since 1992. The CDC reviews new and revised codes twice a year and assigns new disease codes every October.

Why does it matter?

ICD-10 codes are used by clinicians every time they see a patient. They are now stored in the patient's electronic medical records (EMRs), enabling a patient's health information to be more easily shared between clinicians and health care settings. ICD-10 codes are used to track the epidemiology of a disease including demographics, incidence, and treatment outcomes. For rare Developmental Epileptic Encephalopathies (DEEs), having an ICD-10 code enables us to identify patients with these diseases more quickly. The data we can gather from having ICD-10 codes will bolster research, help us identify patients for clinical trials, and enable us to standardize protocols for care.

Without ICD-10 codes, the lack of data makes it difficult to track our diseases effectively and hampers research efforts. Patients in the wider population are not being identified, and may not be receiving the full range of care.

What can we do?

The process of obtaining an ICD-10 code is long and complex. A handful of DEE parent advocacy organizations have been able to obtain codes in the past few years, but many have not. The CDC has not provided a workable solution for potentially hundreds of genetic-based DEEs and other neurodevelopmental disorders.

In response to the growing concern from DEE communities, Dr. David Berglund from the CDC made a revised proposal for a new hierarchy of codes for genetic neurodevelopmental disorders at the March 2024 ICD-10 Coordination and Maintenance Committee Meeting.

RIGHT NOW, PAGs need to do 3 things to encourage acceptance for this proposal:

1. Send these template letters to the AAP, AAN, and other medical associations:
 - a. [Letter to AAPC](#)
 - b. [Letter to AAP Coding](#)
 - c. [Letter to AAP](#)
 - d. [Letter to AAN Coding](#)

- e. [Letter to AAN](#)
 - f. [Letter to APA ID Caucus](#)
 - g. [Letter to APA DSM-5 Coding](#)
 - h. [Letter to APA](#)
 - i. [Letter to AHA Coding](#)
 - j. [Letter to AHA](#)
 - k. Alternatively, a basic template letter is provided here:
[2024 Academy Advocacy Letter Template](#).
 - l. A full list of organizations with contact information is provided here:[2024 Association Contacts for ICD-10 Support](#).
2. Encourage physicians, researchers and parents to submit a comment to the CDC in favor of Dr. Berglund's proposal by May 17, 2024.
- a. A template comment is provided here: [2024 Public Comment Template for F8A](#).
 - b. Email the comment to: <mailto:nchscid10CM@cdc.gov>
 - c. Cc these individuals:
 - i. Dr. David Berglund, zhc2@cdc.gov
 - ii. Captain Monica Leonard, zgf7@cdc.gov
 - iii. Dr. Jeffrey Linzer, jlinzer@emory.edu
 - iv. Amber Freed afreed@slc6a1connect.org
3. Contact the Co-Chairs for the Congressional Rare Disease Caucus:
- a. A template letter is provided here: [2024 ICD-10 Rare Disease Caucus Letter Template](#)
 - b. Email the letter here:
 - i. [Representative Gus Bilirakis](#)
 - ii. [Representative Doris Matsui](#)
 - iii. [Senator Amy Klobuchar](#)
 - iv. [Senator Roger Wicker](#)

We need to fill their inboxes. Paper letters will have an even greater impact if you have the time.

When does this need to be done?

ASAP.

The 60-day public comment period ends May 17, 2024, after which the CDC ICD-10 Coordination and Maintenance Committee meets to discuss and approve codes. We need to move NOW to get support from these groups and elected officials.