Dear GRI Clinician:

We need your help in convincing the CDC to add ICD-10 codes for GRIA, GRIK and GRIN Disorders.

As I'm sure you are aware, ICD-10 codes are invaluable for knowing how many people have been diagnosed with different diseases, for research, for improving patient care, and for identifying sites for clinical trials. There are currently 68,000 different ICD-10 codes for diseases and symptoms, but there are currently no ICD-10 codes for GRI Disorders.

The CDC is currently seeking input on whether to add codes for GRI Disorders.

Please modify the template below and complete the sections highlighted in yellow below. Multiple clinicians can submit on behalf of an clinic or group, or you can remove the first paragraph if you're submitting as an individual.

Please email your signed letter of support to dfp4@cdc.gov and zhc2@cdc.gov on or before *May 5, 2023*.

Thank you for your support!

Kind regards,

Keith McArthur
CureGRIN Foundation
keith@curegrin.org
(416) 357-1249

[Date]
Ms. Donna Pickett
Co-Chair, ICD-10-CM Coordination and Maintenance Committee
National Center for Health Statistics
ICD-10-CM Coordination and Maintenance Committee
3311 Toledo Road
Hyattsville, Maryland 20782

RE: ICD-10 Code for GRI Disorders and other rare neurodevelopmental disorders and DEEs

Dear Ms. Pickett:

[_____] respectfully submits the following comments on the proposed ICD-10-CM code modifications presented at the ICD-10 Coordination and Maintenance (C&M) Committee meeting held in March 2023.

I would like to convey my support for the establishment of an ICD-10 code for GRI disorders (*GRIN1, GRIN2A, GRIN2B, GRIN2D, GRIA1, GRIA2, GRIA3, GRIA4, GRIK2*).

Dr. Timothy Benke presented on behalf of CureGRIN Foundation and GRIN2B Foundation at the C&M meeting. He noted that GRI (Glutamate receptor, ion channel) neurodevelopmental disorders are unique, well-defined syndromes. He noted that there are 9 different syndromes (*GRIN1, GRIN2A, GRIN2B, GRIN2D, GRIA1, GRIA2, GRIA3, GRIA4, GRIK2*) which have different specific therapies.

Relative to many other rare neurological syndromes, other GRI disorders are common neurodevelopmental disorders with birth incidences of 5:100,000 for *GRIN1*, 3:100,000 for *GRIN2A,* 6:100,000 for *GRIN2B*, 5:100,000 for *GRIN2D*, 3:100,000 for *GRIA1*, 3:100,000 for *GRIA2*, 3:100,000 for *GRIA3*, 2:100,000 for *GRIA4*, and 2:100,000 for *GRIK2*, compared to Rett Syndrome (10:100,000) (F84.2) or Dravet (4:100,000) (G40.834) respectively. Many medical practitioners see patients with GRI disorders and currently code for symptoms rather than diagnoses. There are clinical trials for GRI disorders underway, and there is an urgent need to identify GRI cases as new treatments are approved.

I would like to convey my support for the establishment of ICD-10 codes for rare genetic neurodevelopmental disorders, including rare genetic epilepsies. Rare diseases, including genetic epilepsies, are not adequately described by existing ICD-10-CM codes. Lack of a unique code for these disorders results in numerous challenges, including inability to accurately track incidence and prevalence, difficulty in researching genotype-phenotype correlations, and ultimately complicating the development of protocols for standard of care.

I support the inclusion of rare genetic disorders including GRI disorders in ICD-10-CM, and the expansion to the sixth digit to include specific variants. The inclusion of specific ICD codes for rare, genetic epilepsies has the potential to improve patient care, improve communication amongst care teams, and allow for tracking of individual diseases. This is particularly important with the high number of precision therapies in development targeting rare diseases, such as rare genetic epilepsies.

We want to specifically highlight a study by Dianalee McKnight et al. published in JAMA Neurology (doi:10.1001/jamaneurol.2022.365) that shows that a genetic diagnosis for patients with epilepsy changes patient care in half of all cases. This indicates that including a genetic diagnosis for epilepsies may directly impact clinical care. Thus, an ICD-10-CM code that identifies the genetic underpinnings for epilepsies has the potential to improve patient care. Thank you for the opportunity

to comment on the proposed ICD-10-CM code for rare neurodevelopmental diseases and DEEs. If you have any questions, please contact me at _____.

Sincerely,