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DLG4 SHINE Syndrome Achieves Critical Milestone with Assignment of ICD Code

In a landmark advancement for the rare disease community, DLG4-related Synaptopathy has officially been assigned an International Classification of Diseases (ICD) code, marking a pivotal step toward improved diagnosis, data collection, and access to care for thousands of individuals affected by this underrecognized condition.

The ICD system, maintained by the World Health Organization (WHO), serves as the global standard for reporting diseases and health conditions. An ICD code functions as a universal identifier—used by clinicians, hospitals, insurers, and researchers to document and track medical diagnoses. Until now, DLG4 SHINE (SHINE Syndrome) lacked formal recognition within this system, limiting visibility in clinical records and impeding access to appropriate treatment and reimbursement.

“This designation is more than symbolic—it’s systemic,” said Sabrina Merchant, Director of Science & Clinical Development at DLG4 SHINE Foundation. “With an ICD code, patients are no longer invisible. Providers can diagnose with confidence, insurers can process claims accurately, and researchers can build the data sets needed to drive innovation.”

The assignment of the ICD code follows years of coordinated advocacy, scientific collaboration, and policy engagement led by DLG4 SHINE Foundation in partnership with clinicians, researchers, and families across the globe. It represents a critical foundation for future progress, including:

- **Accurate diagnosis and clinical documentation**
- **Expanded access to insurance coverage and reimbursement**
- **Improved tracking of patient outcomes and prevalence**
- **Enhanced eligibility for research funding and clinical trials**

“This milestone validates the lived experience of every patient and caregiver,” said Marie-France Gervais, Co-President at DLG4 SHINE Foundation. “It opens doors to improved care and services, research, and hope.”

The newly assigned ICD code will be included in the upcoming update to 2026 ICD-10 CM and is expected to be adopted by healthcare systems globally.

For more information about DLG4 SHINE Foundation, the ICD code assignment, or ongoing advocacy efforts, please contact:

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