HOUSE RESOLUTION 216

WHEREAS, Schaaf-Yang syndrome (SYS, OMIM #615547) is a rare, life-long neurodevelopmental disorder affecting multiple systems; and

WHEREAS, SYS is caused by truncating mutations in the maternally imprinted, paternally expressed MAGEL2 gene, located in the Prader-Willi syndrome (PWS, OMIM #176270) critical region 15q11-13 (NCBI Gene ID: 54551); and

WHEREAS, Since its identification in 2013, a total of 150+ people worldwide have been identified as living with Schaaf-Yang syndrome; and

WHEREAS, Schaaf-Yang syndrome shares many clinical features with Prader-Willi syndrome, including hypotonia, feeding difficulties during infancy, global developmental delay/intellectual disability, endocrine anomalies, and sleep apnea, but SYS remains distinct because of a higher prevalence of autism spectrum disorder and joint contractures; and

WHEREAS, Schaaf-Yang syndrome is typically diagnosed through whole genome or whole exome sequencing and is not routinely screened for as part of prenatal genetic testing; and

WHEREAS, Currently, no cure exists for Schaaf-Yang syndrome, but children and adults thrive through therapies, specialized care in areas, including sleep medicine and endocrinology, and inclusion; and

WHEREAS, A SYS/MAGEL2 Advisory Group (SMAG) has been established through the Foundation for Prader-Willi Research (FPWR) to further advance research; therefore, be it

RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE HUNDRED FIRST GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that we declare November 1, 2019 as Schaaf-Yang Syndrome Awareness Day to raise awareness, promote inclusion, encourage research, and share hope.