## Need to include disease Lupus under the National policy for Rare Diseases-laid

**SHRI HIBI EDEN (ERNAKULAM):** I would like to draw the attention of this House to the pressing concerns of Lupus patients across the country. Lupus is a rare, chronic, life-threatening autoimmune disease that disproportionately affects women in the age group of 15 to 45, with a striking 9:1 female-to-male ratio. It is incurable and requires lifelong treatment, often involving expensive immunosuppressants and continuous monitoring due to the multi-organ involvement. Despite its severity, Lupus remains excluded from the National Policy for Rare Diseases (NPRD). Patients face numerous challenges: delayed diagnosis due to lack of awareness, the complexity of the disease, demographic vulnerability, social invisibility, and stigma. The burden is further compounded by high treatment costs, lack of insurance coverage, and workplace discrimination or job loss due to unpredictable flares. There is an urgent need to include Lupus in the NPRD, and consider special provisions for subsidized lifelong treatment under central health schemes. Additionally, the Government must ensure disability recognition, insurance inclusion, and workplace protections for Lupus warriors. I urge the Ministry of Health and Family Welfare to take immediate steps to address the systemic neglect of Lupus patients in policy frameworks.