

**Need for comprehensive state specific policy and allocation of adequate funds for rare disease management**

DR. KANIMOZHI NVN SOMU (Tamil Nadu): Sir, as a member from the medical fraternity, I would like to speak on the status of three important diseases for which the Government has to take proactive steps. Haemophilia is a rare congenital bleeding disorder. The blood does not clot in the normal way because it does not have enough blood-clotting proteins. It requires protocol or prophylactic care to prevent bleed. The Government should have a comprehensive programme 'Ashadhara' which is currently under review for approval by the Ministry of Health. There is a need to establish capacity and capability building and monitoring patient outcomes. The Government should announce tax exemption for all drugs for Prophylaxis treatment.

Rare Disease Management is still in a nascent stage. In January, 2021, the Delhi High Court had directed the Union Government to initiate new National Health Policy for Rare Diseases by 31<sup>st</sup> March, 2021. Unfortunately, the Government has made no new allocation for such a plan. There are 70 million people in India with rare diseases. Globally, rare diseases are responsible for 35 per cent of deaths in the first year of life. Thirty per cent of children with rare diseases will not live to see their fifth birthday. These numbers are more drastic in India. Efforts for decentralizing care delivery and maintenance of a public health registry to gather real time information on patients to support research, planning and surveillance is mandatory.

Spinal Muscular Atrophy is a neurodegenerative condition associated with high morbidity and mortality. The Government has to create a hub-and-spoke model with the support of a centre of excellence with special grants to enable better access. Efforts need to be taken to improve the quality of life for patients and caregivers and for a multi-disciplinary approach like co-creating awareness and early detection of SMA and clinical skill building of health care providers. There is a need for comprehensive State-specific policy.

Therefore, I urge the Union Government to provide adequate care and funds for the treatment of Haemophilia, Spinal Muscular Atrophy and other rare disease management. Thank you.

SHRI M. MOHAMED ABDULLA (Tamil Nadu): Sir, I associate myself with the Special Mention made by the hon. Member.

SHRI JAWHAR SIRCAR (West Bengal): Sir, I also associate myself with the Special Mention made by the hon. Member.

SHRIMATI MAHUA MAJI (Jharkhand): Sir, I also associate myself with the Special Mention made by the hon. Member.

DR. SASMIT PATRA (Odisha): Sir, I also associate myself with the Special Mention made by the hon. Member.

SHRI ABIR RANJAN BISWAS (West Bengal): Sir, I also associate myself with the Special Mention made by the hon. Member.

DR. AMAR PATNAIK (Odisha): Sir, I also associate myself with the Special Mention made by the hon. Member.

SHRIMATI JEBI MATHER HISHAM (Kerala): Sir, I also associate myself with the Special Mention made by the hon. Member.

SHRI RAKESH SINHA (Nominated): Sir, I also associate myself with the Special Mention made by the hon. Member.

DR. JOHN BRITTAS (Kerala): Sir, I also associate myself with the Special Mention made by the hon. Member.

DR. V. SIVADASAN (Kerala): Sir, I also associate myself with the Special Mention made by the hon. Member.

SHRIMATI VANDANA CHAVAN (Maharashtra): Sir, I also associate myself with the Special Mention made by the hon. Member.

DR. FAUZIA KHAN (Maharashtra): Sir, I also associate myself with the Special Mention made by the hon. Member.

SHRI SANDOSH KUMAR P (Kerala): Sir, I also associate myself with the Special Mention made by the hon. Member.

#### **Need for strict law to control increasing population in the country**

**डा. किरोड़ी लाल मीणा** (राजस्थान) : उपसभाध्यक्ष महोदय, मैं बढ़ती हुई जनसंख्या से देश में उत्पन्न होने वाले संकट के संबंध में बोलने के लिए खड़ा हुआ हूँ।