महोदय, मैं एक और चीज़ कहना चाहूंगा कि आय के असमान वितरण का स्वास्थ्य जैसे विषयों पर भी असर पड़ता है, शिक्षा पर भी असर पड़ता है। मैं सदन को आगाह करता रहा हूं कि अगर हमने इसके लिए कठोर और तात्कालिक फैसले नहीं लिए, तो हम एक ज्वालामुखी के ढेर पर बैठे हुए हैं।

महोदय, मैं आखिर में कहूंगा कि आर्टिकल 38 और आर्टिकल 39 का संज्ञान लें। मैं कहूंगा कि खास कर आर्टिकल 39, क्लाज़ 'सी' -that the operation of the economic system does not result in the concentration of wealth and means of production to the common detriment. That is my request to you and to the Government. Thank you very much, Sir.

THE VICE-CHAIRMAN (SHRI GHANSHYAM TIWARI): The following hon. Members associated themselves with the matter raised by Shri Manoj Kumar Jha: Dr. John Brittas (Kerala), Dr. V. Sivadasan (Kerala), Shri P. P. Suneer (Kerala), Shri Jose K. Mani (Kerala), Shri A. A. Rahim (Kerala), Shri Sandosh Kumar P (Kerala), Shri Haris Beeran (Kerala), Shri Prakash Chik Baraik (West Bengal), Shri Saket Gokhale (West Bengal), Shri Ritabrata Banerjee (West Bengal), Shri Sanjay Yadav (Bihar), Dr. Fauzia Khan (Maharashtra), Shrimati Mahua Maji (Jharkhand), Shri Sujeet Kumar (Odisha), Dr. Sasmit Patra (Odisha) and Shri M. Mohamed Abdulla (Tamil Nadu).

Demand to provide funds for the research and development of low-cost gene therapy for Spinal Muscular Atrophy (SMA)

SHRI HARIS BEERAN (Kerala): Mr. Vice-Chairman Sir, I wish to draw the attention of this august House to the sufferings of patients affected by Spinal Muscular Atrophy, which I refer to as SMA. The SMA is a very rare genetic disorder that affects the nerve cells in the spinal cord. This condition is diagnosed in infancy, typically before six months. If left untreated, it is the primary cause of death. According to estimated statistics, approximately 8,000 to 25,000 people are affected by SMA every year in India. There is, however, a positive development. Treatments are available to manage SMA, although there is no cure. Three types of treatments exist. Firstly, gene therapy is available for infants below two years. Secondly, there is an injection-based treatment. Thirdly, molecule therapy is also an option. However, the downside is that these treatments are exorbitantly priced. The gene therapy costs around 17 crore rupees, which is the cost of the gene therapy medicine. The molecule therapy medicine costs around 6.2 lakh rupees per bottle, with around 30 bottles required per year. Consequently, these treatments are unaffordable for most of the people.

Therefore, I suggest that the Ministry of Health and Family Welfare must intervene urgently.

Experts have suggested that local production of these medicines, specifically generic versions, is feasible. Indian pharmaceutical companies are well-equipped to produce such generic medicines. To facilitate the production of generic medicines, an exemption under Section 100 of the Patents Act is necessary. Experts claim that producing generic medicines locally could reduce the cost of one bottle of medicine from rupees 6.2 lakhs to rupees 3,063. I must refer to the National Policy for Rare Diseases 2021, which stipulates that local manufacture of medicines for rare diseases is permitted. Therefore, I urge upon the Government to invoke this policy to allow local production of generic medicines.

Furthermore, Sir, two additional points need to be addressed. Firstly, a registry for SMA patients is essential. Currently, crowd-funding is the sole means of support for these patients, which is insufficient. Therefore, an SMA registry must be established. Secondly, until local production of medicines commences, the Government should subsidize these medicines or make them customs duty-free so that, at least, there is...*(Time-bell rings)*...

THE VICE-CHAIRMAN (SHRI GHANSHYAM TIWARI): Your three minutes are over, thank you, Mr. Haris.

The following hon. Members associated themselves with the matter raised by the hon. Member, Shri Haris Beeran: Shri Anil Kumar Yadav Mandadi (Telangana), Shri Jose K. Mani (Kerala), Shri P.P. Suneer (Kerala), Shrimati Jebi Mather Hisham (Kerala), Dr. John Brittas (Kerala), Shri Sanjeev Arora (Punjab), Dr. V. Sivadasan (Kerala), Dr. Fauzia Khan (Maharashtra), Shri Sanjay Singh (Delhi), Shri A.A. Rahim (Kerala), Ms. Swati Maliwal (Delhi), Shrimati Mahua Maji (Jharkhand), Dr. Sasmit Patra (Odisha), Shri Abdul Wahab (Kerala), Shri Imran Pratapgarhi (Maharashtra), Shri Saket Gokhale (West Bengal), Shri Sandosh Kumar P (Kerala), Shri Meda Raghunandha Reddy (Andhra Pradesh) and Shri M. Mohamed Abdulla (Tamil Nadu). Next, Shri Sanjay Kumar Jha.

Demand to rename Darbhanga Airport as Kavi Kokil Vidyapati Airport

श्री संजय कुमार झा (बिहार): आदरणीय उपसभाध्यक्ष महोदय, मैं धन्यवाद देना चाहता हूँ। दरभंगा एयरपोर्ट उड़ान स्कीम का देश का सबसे सक्सेसफुल एयरपोर्ट है। यह प्रधान मंत्री जी की परिकल्पना थी कि जो छोटे एयरपोर्ट्स हैं, उन्हें उड़ान स्कीम के अंतर्गत डेवलप करना है। अब लोग वहाँ से भी बहुत बड़ी संख्या में ट्रेवल करते हैं। इसी तरह से, वित्त मंत्री जी ने इस बार के बजट में भी इसे दस साल extend कर दिया है और सौ नई जगहों को टेक-अप करने की बात है।