अभियान चलाया था। महोदय, हमारे पास एक अमेरिकन नागरिक भी थे - सैमुअल स्टोक्स, जिन्हें हम 'सत्यानंद जी' के नाम से जानते हैं।

महोदय, भारत की सांस्कृतिक चेतना ने इन सभी को सिर्फ राजनीतिक आंदोलन का ही हिस्सा नहीं बनने दिया, बल्कि वे भारतीय संस्कृति, विरासत और इतिहास से भी जुड़ गए थे। उन्होंने भारत माता को अपनी माँ के रूप में स्वीकार किया।

महोदय, इन्हीं में एक और नाम मार्गरेट एलिजाबेथ नोबल का आता है, जिन्हें हम 'सिस्टर निवेदिता' के नाम से जानते हैं। उन्होंने भी अपने आपको भारत की आध्यात्मिक चेतना से जोड़ते हुए भारतीयों में आध्यात्मिक चेतना के सूचकांक को बढ़ाने का काम किया था। वे स्वामी विवेकानंद जी की शिष्या थीं। इसी प्रकार से एक और नाम है - मीरा अल्फोंस, जिन्हें हम 'मदर' के नाम से जानते हैं। मेरा सरकार से निवेदन है कि ऐसे विदेशी नागरिकों द्वारा दिए गए योगदान पर ध्यान दिया जाए।

माननीय उपसभापति जी, आपने मुझे अपनी बात रखने का अवसर दिया है, इसके लिए आपका बहुत-बहुत धन्यवाद।

श्री उपसभापतिः राकेश सिन्हा जी, आपका बहुत-बहुत धन्यवाद। The following hon. Members associated themselves with the matter raised by the hon. Member, Shri Rakesh Sinha: Shri Sujeet Kumar (Odisha), Dr. Sasmit Patra (Odisha), Shri Deepak Prakash (Jharkhand), Shri Kanakamedala Ravindra Kumar (Andhra Pradesh), Shri Jawhar Sircar (West Bengal), Shri Dhananjay Bhimrao Mahadik (Maharashtra), Dr. Santanu Sen (West Bengal), Shri Sandosh Kumar P (Kerala), Dr. Amar Patnaik (Odisha), Shri Abir Ranjan Biswas (West Bengal) and Shri Maharaja Sanajaoba Leishemba (Manipur).

Now, Shri Kartikeya Sharma. Strengthening of ecosystem for diagnosis, treatment and rehabilitation of patients suffering from rare and genetic disorder.

Strengthening of ecosystem for diagnosis, treatment and rehabilitation of patients suffering from rare and genetic disorders

SHRI KARTIKEYA SHARMA (Haryana): Thank you, Deputy Chairman, Sir, for allowing me to raise this very important issue of public importance. India is a large country with over 140 crore population. As a result, the number of cases of rare and genetic disorders is also huge. As per Government estimates, about 7.2 crore to 9.6 crore Indians suffer from 6,000 different rare or genetic diseases in the country. These include diseases like Sickle Cell Anemia, Spinal Muscular Atrophy, Down Syndrome and Cystic Fibrosis, etc. The field of rare diseases is complex and heterogeneous. The landscape of rare diseases is constantly changing, as there are new rare diseases and conditions being identified and reported regularly in medical literature.

There are primarily three challenges. First category of challenge is related to diagnosis. There is lack of awareness about rare diseases in general public as well as in the medical fraternity. Since most of the case load is in tier 2, 3 and 4 cities and towns and rural areas, they remain undetected and undiagnosed. In addition, two to three mis-diagnoses are typical before arriving at a final diagnosis which causes delay and further suffering.

Second category of challenge is related to treatment. Despite progress in recent years, effective or safe treatment is not available for most of these rare diseases. The other critical factor is the prohibitive cost of treatment. For the rare disease called Spinal Muscular Atrophy, the treatment involves a drug called 'zolgensma', which costs a whopping amount of Rs. 18 crore. Drugs like Nitisinone are used for the treatment of Tyrosinemia Type 1 and costs more than Rs. 3 crore per annum. Recently, the Government has given permission for manufacturing of four out of the eight types of generic drugs for the treatment of rare genetic diseases such as Tyro-sinemia Type, Gaucher's Disease, Wilson's Disease, etc. Two 2 MG tablet that costs Rs. 5 lakhs from Sweden will be available for Rs. 6,500 in India. The drug Eliglustat that costs more than 3 crore of rupees a year shall now cost about 5 lakh of rupees. So is the case with other drugs. This is a welcome and a much-needed move.

Third category of challenge is Prevention and Control of Rare Diseases. The prevention of genetic disorders can be done at multiple levels, namely, build the capacity of health professionals and increase awareness in the population at large; preventing the occurrence of the disease, that is, preventing two carriers from reproducing; pre-natal screening and pre-natal diagnosis; new-born screening; and, better care and medical rehabilitation to the patients.

Although the Government is doing its best, I would like to make three suggestions. First is, gather more and more epidemiological data on how many people are suffering from which rare and genetic disorder, prevalence and burden of diseases, patterns and trend analysis and align policy measure to it, and, second is...

MR. DEPUTY CHAIRMAN: Time is over. Thank you. The following hon. Members associated themselves with the matter raised by the hon. Member, Shri Kartikeya Sharma: Shrimati Vandana Chavan (Maharashtra), Dr. Sasmit Patra (Odisha), Shri Sanjeev Arora (Punjab), Shrimati Mahua Maji (Jharkhand), Shri M. Shanmugam (Tamil Nadu), Dr. Fauzia Khan (Maharashtra), Shri Kanakamedala Ravindra Kumar (Andhra Pradesh), Shri Dhananjay Bhimrao Mahadik (Maharashtra), Dr. John Brittas

(Kerala), Dr. Santanu Sen (West Bengal), Dr. V. Sivadasan (Kerala), Prof. Manoj Kumar Jha (Bihar), Shri Sant Balbir Singh (Punjab), Shri Sandosh Kumar P (Kerala), Dr. Amar Patnaik (Odisha), Shri Abir Ranjan Biswas (West Bengal) and Shri Vivek K. Tankha (Madhya Pradesh).

Now, Shri Sanjeev Arora; Demand to Reconsider Decision of not imposing Anti-Dumping Duty on Imported Polyester Spun Yarn.

Demand to reconsider the decision of not imposing Anti-Dumping Duty on imported Polyester Spun Yarn

SHRI SANJEEV ARORA (Punjab): Thank you, Mr. Deputy Chairman, Sir, for giving me permission to speak on a very important issue. It is regarding textile industry which is one of the largest employers in the country. The textile industry is going through a very bad phase. It is running at around 50 per cent on an average capacity nationwide. An immediate action is required from the Textile Ministry and the Finance Ministry. More than 45 million workers are directly employed by the industry, not to talk about indirect beneficiaries. We are staring at a huge unemployment on our way and also huge amount of NPAs in the shape of bad loans. To save the industry, we need to make import of cotton and polyester fibre cheaper, rather it should be duty free, and anti-dumping duty should be imposed on duty free imports of polyester yarn from the countries falling under Asian FTA. This request has been made by all the associations many times. I have also personally requested the hon. Finance Minister before also. Export incentives need to be given which should be unprecedented. There is a need to help the industry and also further help to 'Make in India' mission by making raw material cheaper and finished products costlier to get into this country. Thank you, Sir.

MR. DEPUTY CHAIRMAN: The following hon. Members associated themselves with the matter raised by the hon. Member, Shri Sanjeev Arora: Dr. L. Hanumanthaiah (Karnataka), Dr. Amar Patnaik (Odisha), Dr. Sasmit Patra (Odisha), Shri Abir Ranjan Biswas (West Bengal), Dr. Ashok Kumar Mittal (Punjab), Shri M. Shanmugam (Tamil Nadu), Shri Sandeep Kumar Pathak (Punjab), Shri Sushil Kumar Gupta (National Capital Territory of Delhi), Dr. John Brittas (Kerala), Dr. Santanu Sen (West Bengal) and Dr. Fauzia Khan (Maharashtra).