The oocyte donor shall be an ever married woman, having atleast one live child of her own, not below the age of three years and may donate oocytes only once in her life.

(d) Yes. The proposed Assisted Reproductive Technology (Regulation) Bill, 2019 is being placed before the Cabinet for approval and subsequently for its introduction in the Parliament.

Tackling rare diseases

254. DR. K.V.P. RAMACHANDRA RAO: Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) whether it is in the notice of Government that several people are suffering from rare diseases requiring special attention and lifelong treatment;

(b) if so, the details thereof; and

(c) whether Government is taking any step to identify the persons with the rare diseases and extend possible help to them, if so, the details thereof?

THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (SHRI ASHWINI KUMAR CHOUBEY): (a) to (c) Government is aware of cases of people suffering from rare diseases. However, data on how many people suffer from different diseases, which are considered rare globally is lacking in India.

Government of India had formulated a National Policy for Treatment of Rare Diseases (NPTRD) in July, 2017. However, due to implementation challenges, the said policy was kept in abeyance till the revised policy was issued or till further orders, whichever was earlier. An Expert Committee was constituted by Ministry of Health and Family Welfare to review the NPTRD, 2017 and draft National Policy for Rare Diseases. Based on the report of the Expert Committee and with the approval of the competent authority, draft of the National Policy for Rare Diseases has been finalized and placed on the website of the Ministry of Health and Family Welfare to elicit comments/views of the stakeholders, including the States/UTs and the general public by 15-02-2020.

The draft policy *inter alia* provides that Government will have a National Registry for Rare Diseases at Indian Council of Medical Research (ICMR) with the objective of creating a database of various rare diseases. Steps have already been taken in this direction by ICMR.

The draft policy also provides for lowering the incidence and prevalence of rare diseases based on an integrated preventive strategy encompassing awareness generation and screening programmes and, within the constraints on resources and competing health care priorities, enable access to affordable health care to patients of rare diseases which are amenable to one-time treatment.

Comprehensive sexuality education

255. SHRIMATI VANDANA CHAVAN: Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a)   whether Government is aware that as a signatory to the International Conference on Population and Development (ICPD) Programme of Action 1994, India is obligated to provide reproductive health education or Comprehensive Sexuality Education (CSE) to adolescents;

(b)   if so, whether Government has taken any step for the same, including any national programmes/schemes currently in place to impart CSE to adolescents in schools and out-of-school settings; and

(c)   if not, the reasons therefor?

THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (SHRI ASHWINI KUMAR CHOUBEY): (a) to (c) Yes.

Government of India is implementing the Adolescence Education Programme (AEP) through State AIDS Control Societies in coordination with SCERT using a 16 hours curriculum based module developed by NCERT; for adolescents in both inside and outside formal schools.

The programme aims to empower adolescent learners to acquire knowledge of their needs and concerns related to the period of adolescence and develop life skills that enable them to practice informed and responsible behaviours. Adolescents are equipped with accurate information, knowledge and skills in the specific contexts of the process of growing up and prevention of HIV/AIDS.

Besides this, there is comprehensive integration of the adolescent health needs and concerns into the school education and teacher education system.