### GOVERNMENT OF INDIA MINISTRY OF HEALTH AND FAMILY WELFARE DEPARTMENT OF HEALTH AND FAMILY WELFARE

## LOK SABHA UNSTARRED QUESTION NO. 2929 TO BE ANSWERED ON 3<sup>rd</sup> AUGUST, 2018

#### SICKLE CELL ANAEMIA

#### 2929. DR. SUNIL BALIRAM GAIKWAD:

#### Will the Minister of **HEALTH AND FAMILY WELFARE** be pleased to state:

- (a) whether the Government proposes to launch a programme for prevention and control of sickle cell anaemia, thalassemia and haemophilia in the country;
- (b) if so, the details thereof along with the time by which the programme is likely to be launched;
- (c) the extent of financial and technical assistance/commodities being provided by the Government to the States/UTs for the investigation, prevention and control of the aforesaid blood disorders during the last three years and the current year; and
- (d) the measures being taken by the Government to promote research in order to develop therapy of hereditary blood disorders through stem cell in the country?

# ANSWER THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (SMT. ANUPRIYA PATEL)

- (a): Public Health and Hospitals is a state subject. Under the National Health Mission, support is already being provided to States/UTs to strengthen their healthcare systems including for prevention and management of sickle cell anaemia, thalassemia and haemophilia based on the proposals submitted by the State/UT Governments in their Programme Implementation Plans.
- (b): Does not arise in view of answer to (a) above.
- (c): The details of support provided to 27 States/UTs in the last three years are at Annexure-I.
- (d): The information as provided by ICMR is at Annexure-II.

# **Budget for Blood Disorders for 3 years**

(Rs in Lakhs)

S.No	State	Budget for Blood Disorder for 2015-16	Budget for Blood Disorder for 2016-17	Budget for Bloo Disorder for 2017-18
1	Uttarakhand	0	122.86	385.46
2	<b>Uttar Pradesh</b>	0	2030.66	3069.11
3	Gujarat	532.93	0	430
	Kerala	0	47.87	0.79
4	Chhattisgarh	0	292	129.9
5	Odisha	249.61	100.84	391.81
6	Himachal Pradesh	0	7.5	0
7	Maharashtra	4330.7	1455.24	1397.22
8	Jharkhand	0	391.85	1.5
9	Tripura	0	100	0
10	Haryana	0	1164.56	197.2
11	Dadar Nagar Haveli	0	0	4.97
12	Delhi	0	0	75
13	Tamil Nadu	0	230.76	80
14	Assam	0	0	18.5
15	Manipur	0	85	0
16	Punjab	0	0	500
17	Rajasthan	329	346	100.1
18	Arunachal Pradesh	0	14.14	50
19	Goa	0	4.78	0
20	Bihar	0	31.43	27.92
21	Karnataka	0	964.4	1412.4
22	Telangana	0	100.3	0
23	Madhya Pradesh	0	1139.5	0
24	Andhra Pradesh	112	825.62	172.72
25	West Bengal	0	2217.03	1800
26	Jammu & Kashmir	15	20	62.54
27	Nagaland	0	20.55	0
	Total	5569.24	11712.89	10307.

Source: State approvals

ICMR's efforts have been on the following areas towards thalassemia control:

- Neonatal screening
- Prenatal diagnosis for thalassemia
- Training and quality control for prenatal and neonatal screening
- Molecular characterization of hemoglobinopathies
- Bone Marrow Transplant (BMT) clinical trial for hemoglobinopathies
- National Registry for thalassemia Awareness and education

ICMR also established satellitecentre for Hemogloginopathies in Chandrapur, Maharashtra. The major objectives of this centre are to undertake community control program and basic research in hemoglobinopathies to benefit the local population and to develop human resources who can further carry out the work in other regions of the country wherehemoglobinopathies is a major health burden. More than 600 sickle cell disorders patients have been identified andfollowed upregularly for care and better managements. Antennal screening of more than 9000 women has identified 40 high risk couples who were offered prenatal diagnosis at ICMR-NIIH, Mumbai. Newborn screening has also been initiated where over 1000 babies havebeen screened and 4 babies with SCD and 85 with Sickle Cell carrier have been identified. Multiple research programmes in pathophysiology of SCD have also been undertaken.

ICMR has established centres for molecular diagnosis for prevention and control of hemoglobinopathies at following institutes by providing infrastructure and technical assistance:

1. CMC Ludhiana, Punjab 2. NRS Medical College, Kolkata, West Bengal. 3. Valsad and SuratRaktdan Kendra, Gujarat 4. St John's Medical College, Bangalore, Karnataka 5. Govt. Medical College, Nagpur, Maharashtra.

ICMR- NIIH Mumbai also has a prenatal diagnosis facility for sickle cell disease and currently the technology is being transferred to ICMR's institutes, NIRTH Jabalpur and RMRC Dibrugarh which will ultimately benefit the tribal population of these states.

Govt. agencies including ICMR, DBT, DST and CSIR are supporting and promoting research in the field of Stem Cell Research.

ICMR is promoting basic as well as clinical research through open ended projects as well as Task Force mode stem Cell research is one of the priority areas of ICMR