

## SICKLE CELL ANAEMIA CONTROL PROGRAM – A GUJARAT GOVERNMENT INITIATIVE

### Background

Sickle Cell Anaemia (also known as Sickle Cell Disorder or Sickle Cell Disease) is a genetic blood disorder, where the blood cells contain abnormal sickle shaped haemoglobin (HbS) called sickle haemoglobin. Prevalence of Sickle Cell gene is estimated to be 5 to 34 % in scheduled tribes. India has also a very large population of tribal community of about 180 million and expected to have 18 million, sickle cell trait and 1.4 million, sickle cell disease.

### Sickle Cell Anemia Control Program of Gujarat

Gujarat has 8.912 million tribal populations and is expected to have at least 900 thousand Sickle Cell Trait and 70 thousand Sickle Cell Disease patients. According to ICMR survey amongst the primitive tribes of south of Gujarat; 30 % of Sickle Cell Disease children die before they reach adulthood (14 years) and the remaining 70 % die by the age of 50.

During 2005-06, a Comprehensive Sickle Cell Program based on public-private partnership was started in 4 tribal districts and now it has been extended to all 12 tribal districts of Gujarat in 2008 from Ambaji to Dang in eastern belt.

### Gujarat Sickle Cell Anemia Control Society:

In the year, 2011 Gujarat Sickle Cell Anaemia Control Society was formed to integrate the various activities among different departments of Government and various

NGOs for better implementation of the program under Chairmanship of the Health Minister and Co-chairmanship of the Minister of Tribal Development Department.

### Goal

- No Child birth with Sickle Cell Disease by 2020.
- Prevention of death from Sickle Cell Anemia
- To improve health status and quality of life of Sickle Cell Anemia patients.

### Activities Carried Out in Program

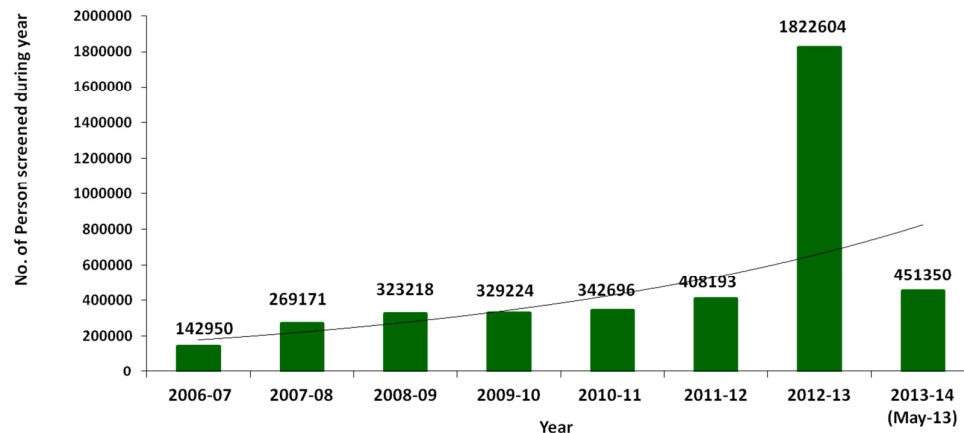
The activities carried out in this program to reduce the morbidity and mortality due to Sickle Cell Anemia. In program early diagnosis is done through Mass Screening on mission mode, New Born Screening, Prenatal Diagnosis, Antenatal Screening, Adolescent Screening and thus covering all age group showing lifecycle approach. Marriage Counselling & Genetic Counselling helps in prevention of disease to transfer into next generation. Regular training and capacity building of health staff as well as the NGO staff, ASHA & VHSNC members are done for building awareness. Supportive treatment, follow up, Daily Folic Acid supplementation, Lifesaving Hydroxyurea therapy and vaccination help in reducing crisis of SCD patient.

### New Approach

As per decided in Governing Body of Gujarat Sickle Cell Anaemia Control Society, Screening procedure has been outsourced to qualified, competent and dedicated competitive agencies by two bid process. These agencies do the screening work in villages at field level and training has been given to all the staff of these agencies. Before 2012, in this program about 3.5 to 4 lakh populations were screened per year, but after outsourcing more than 18 lakh populations have been screened in one year. Prophylactic pneumococcal

vaccine is given to all SCD patients, more than 7000 SCD patients has been covered. Regular follow up camps for SCD patients are done at quarterly interval at block level. Web based application is being made for Data collection and online tracing of any SCD patient. Govt. of Gujarat has signed MOU with GIOSTAR, USA based company for creating stem cell treatment facilities at Govt. Medical College, Surat. Stem cell transplantation will bring a hope of survival for all Sickle cell disease patients in Gujarat.

### Year wise Community screened for Sickle Cell Anemia in Gujarat, Year 2006 to 2013



### Justification for National Program

As India have one of the largest tribal communities in the world and thus have the highest number of Sickle gene carriers in the world, >50% of the world. As per survey by ICMR, mortality in Sickle Cell disease children is very high. Being genetic in nature, the numbers are bound to rise, if suitable intervention is not made. There are Different views among the experts in world regarding

this disease, so it is required to have universal guideline. Sickle Cell Anaemia being a tribal specific problem, illiteracy in these ethnic groups poses a major threat to success of program. Low level of awareness is a major setback and intensive efforts are required to create awareness and empower tribal population to take informed decision. And so Integration between different departments of Government sectors and various dedicated

NGOs is needed. These all issues justify the need of National Sickle Cell Anaemia Control.

### Recognition

Sickle Cell Anaemia Control Program of

Gujarat state was honoured by “Prime Minister Award for Excellence in Public Administration” by Department of Administrative Reforms and Public Grievances, Government of India.

