Project Profile

Thalassemia Control & Prevention

Gujarat CSR Authority

Project Profile – Thalassemia Control & Prevention

Background & Rationale

Thalassemia is a blood disorder that affect the body's ability to produce haemoglobin and red blood cells (RBC). People with Thalassemia have 'lower than usual' RBCs in their bodies and consequently low levels of the protein - haemoglobin. Lack of RBCs lead to infection, bone deformities, enlargement of the spleen and slower growth rates. Its treatment involves frequent blood transfusions, which can also lead to increased amounts of iron in the blood (although it can also happen because of the disease itself), which then, has to be dealt with medication. There are two main types of thalassemia, **alpha** thalassemia and **beta** thalassemia.

- **Alpha thalassemia**: There are two genes (one from each parent) that produce alpha globin chains. Alpha thalassemia trait occurs if one or two of the four genes are affected.[1]
- **Beta thalassemia**: Two genes (one from each parent) are needed to produce sufficient beta globin protein chains. Beta thalassemia occurs if one or both genes are altered. The severity of beta thalassemia will depend on the number of affected genes. If both genes are affected it results in thalassemia major and severe anaemia.[2]

Diagnosis is typically done by blood tests including a complete blood count, special haemoglobin tests and genetic tests. Diagnosis may occur before birth through prenatal testing. The other common blood disorders that can be detected by testing are Haemoglobinopathies and sickle cell anaemia.

Around 10 to 15,000 babies with Haemoglobinopathies are born in India every year. The burden of hemoglobinopathies in India is high with nearly 12,000 infants being born every year with a severe disorder. These numbers imply that every hour a child is born who will suffer with this genetic disorder.[3] With respect to sickle cell anaemia, the average frequency of sickle cell gene, a group of blood disorders typically inherited from a person's parents, is around 5% in India and the highest sickle cell gene in different states of India are among Orrisa, Assam, Madhya Pradesh, Uttar Pradesh, Tamil Nadu and Gujarat. The table no. 1 depicts the prevalence of sickle-cell disease across these states.[4]

Table 1: Prevalence of sickle-cell anaemias across different states in India

State	Population (%)
Orissa	9.00%
Assam	8.30%
Madhya Pradesh	7.40%
Uttar Pradesh	7.10%
Tamil Nadu	7.10%
Gujarat	6.40%

The affected population of Gujarat from sickle-cell disease is 6.4% against the national average, 5%.

[1] *https://www.nhp.gov.in/thalassemia_pg*
[2] *https://www.nhp.gov.in/thalassemia_pg*
[3] *Thalassemia Sickle Cell Society, Hyderabad, India*
[4] *Source: National Journal of Community Medicine Vol 3 Issue 1 Jan-March 2012*

It is estimated that there are 35 million carriers of Thalassemia i.e. 1 in every 25 Indians. The carrier rate for β - thalassemia varies from 1% to 17 % in India with an average of 3.2 %.[5] Both alpha and beta thalassemia include the following two forms of Thalassemia condition:

- **Thalassemia minor**
  - Thalassemia minor is not a disease and there are no physical sign and symptoms of the disease, as it cannot be identified without a blood test.
  - Thalassemia minor never gets transformed into thalassemia major.
  - No medication or treatment is required for thalassemia minor. One should consult a doctor for further advice.
- **Thalassemia major**
  - Within 3 to 8 months of birth, signs of blood deficiency start to appear in a thalassemia major patient.
  - The person suffering from this disease needs regular blood transfusion during his/her short life-span.
  - Thalassemia major is a fatal disease. In spite of an expensive and long treatment, survival of the patient beyond 20 years is usually difficult.

There is a genetic, ethnic and regional diversity of haemoglobin variants as well as of mutations in India. The marriage of couples from the same ancestry may increase the chances of blood disorder traits in the coming generation. The prevalence of thalassemia is at a rate of 8.1%, 7.9% and 6.5% in the state is especially high in the Thakker community that is sub categorised as Bhanushali (Kutch), Bhatiya (Kutch) and Lohana (Saurashtra) communities, respectively against a state average.[6]

Table 2 & 3 depict the prevalence of common haemoglobinopathies and beta (ß) - thalassemia trait in tribal and non-tribal districts of Gujarat.

Table 2: Prevalence of common haemoglobinopathies in tribal districts of Gujarat

Districts	Number	ß-thalassemia trait (%)
Banaskantha	9,489	423(4.45)
Baroda	31,608	381(1.2)
Bharuch	19,373	330(1.7)
Dahod	15,975	410(2.57)
Narmada	31,966	464(1.45)
Panchmahal	23,077	422(1.83)
Sabarkantha	37007	505(1.37)
Total	**1,68,495**	**2,935 (1.76)**

Source: National Journal of Community Medicine Vol 3 Issue 1 Jan-March 2012

Table 3: Prevalence of common haemoglobinopathies in non-tribal districts of Gujarat

Districts	Number	ß-Thalassemia trait (%)
Ahmedabad	19,825	678 (3.40)
Anand	24,329	482 (1.98)
Gandhinagar	3,165	71 (2.24)
Bhavnagar	1,009	28 (2.77)
Amreli	468	14 (2.99)

[5] *Source: National Journal of Community Medicine Vol 3 Issue 1 Jan-March 2012*
[6] *http://indianexpress.com/article/cities/ahmedabad/prevention-against-thalassemia-health-dept-initiates-community-identification-plan-to-rope-in-ngos/*

Districts	Number	ß-Thalassemia trait (%)
Jamnagar	864	30 (3.47)
Kheda	1,812	45 (2.48)
Kutch	2,476	102 (4.10)
Navsari	12,175	230 (1.89)
Mehsana	31,161	432 (1.36)
Patan	12,691	173 (1.36)
Rajkot	2,284	70 (3.10)
Surat	31,368	732 (2.33)
Porbandar	725	21(2.89)
Surendranagar	1,042	8 (0.77)
Valsad	3,625	145 (4.00)
Total	**1,49,044**	**3,261 (2.18)**

Source: National Journal of Community Medicine Vol 3 Issue 1 Jan-March 2012

Apart from blood transfusions and iron chelation therapy, there is no known cure for this blood disorder. Bone marrow transplantation is the only option for cure. However, even if the child is operated, the chances of survival are only 50%. Also, transplantation treatment is highly expensive and is out of reach for the most marginalized families. Hence, it is imperative that appropriate awareness, affordable screening and treatment facilities are made available for the prevention and cure of Thalassemia especially among the poor and marginalized.

Objectives of the project:

The broader aim of this project is to create awareness, counselling and ensure mandatory screening for Thalassemia among the pre-marital youth, women in their first trimester and for high risk communities. This could help informing the community about the disease, overcome the stigma of being a carrier of the disorder and prevent the spread of the disease in future generations. The objectives are to :

- prevention of Thalassemia through facilitation of pre-marital screening tests for youth of the society, pregnant women and other community members who have high risk of Thalassemia
- counsel individuals and community members to create public awareness regarding Thalassemia and prevent Thalassemia major births in future generation, and to
- impart the knowledge, skills through training for prevention of blood related diseases and information on the latest developments.

Expected Benefits

The support provided would result in tangible and intangible benefits for the Sponsor as outlined below:

Tangible Benefits	Intangibles
❖ Stronger relations within communities through stakeholder engagement ❖ Community support & appreciation, enhancing the Social license to operate ❖ Recognition through awards	❖ Enhanced reputation by way of supporting projects benefitting communities at the bottom of pyramid ❖ Social branding ❖ Enhanced credibility within community and sector ❖ Contribute towards the universal healthcare coverage goal for Thalassemia

Opportunities for CSR intervention

A very small percentage of the thalassemic children in India receive optimal treatment, with access to optimal medical treatment and transfusion facilities often being restricted to people living in the urban

areas. Thus for 65% (approx.) of the Indian population residing in rural areas 'blood disorder trait' poses an immeasurable, emotional, psychological and economic burden on the family. With low levels of awareness and a knowledge challenged society, it is imperative that we first need to enhance awareness on Thalassemia as a genetic blood disorder. Thus, the scope for CSR intervention has been outlined to fund the project for ensuring preventive healthcare among the rural population for Thalassemia.

Branding or visibility proposition for funding partner

By sponsoring the Thalassemia screening programme, the funding partner shall get visibility in the following ways:

- the project will be named under the CSR initiative of the sponsoring company and activities will be undertaken under this head
- the website of implementing agency, blog and other social networking sites will be updated mentioning support extended by the corporate
- progress report(s) of the activities under the project along with photographs of the screening camps shall be shared with the funding partner on a quarterly, half yearly and annual basis.

Potential project area

The project can be implemented at any location across Gujarat. However companies could decide on the areas which could be given priority for implementing the project.

Target Group

The following groups of people shall be screened during the blood screening test:

- pre-marital youth (18-25 years of age)
- women in their first trimester
- individuals belonging to high risk communities
- any individual with a raised RBC (Red Blood Cell) Count and corresponding decrease in Hb (Haemoglobin), MCV (Mean Corpuscular Volume) and MCH (Mean Corpuscular Haemoglobin) values.

Project implementation

A. Implementation

The implementation can be done in the following way:

1. The project shall be implemented by certified agency/NGO, undertaking blood screening projects and having prior experience of organising health camps, in partnership with concerned department (Health and Family Welfare department). Academic institutions, universities and colleges shall also be brought in to support the implementing partner by way of mobilising the students and providing space for organising the awareness sessions and camps on thalassemia.
2. The estimated project cost is given in Table no. 3.

Process of Implementation:

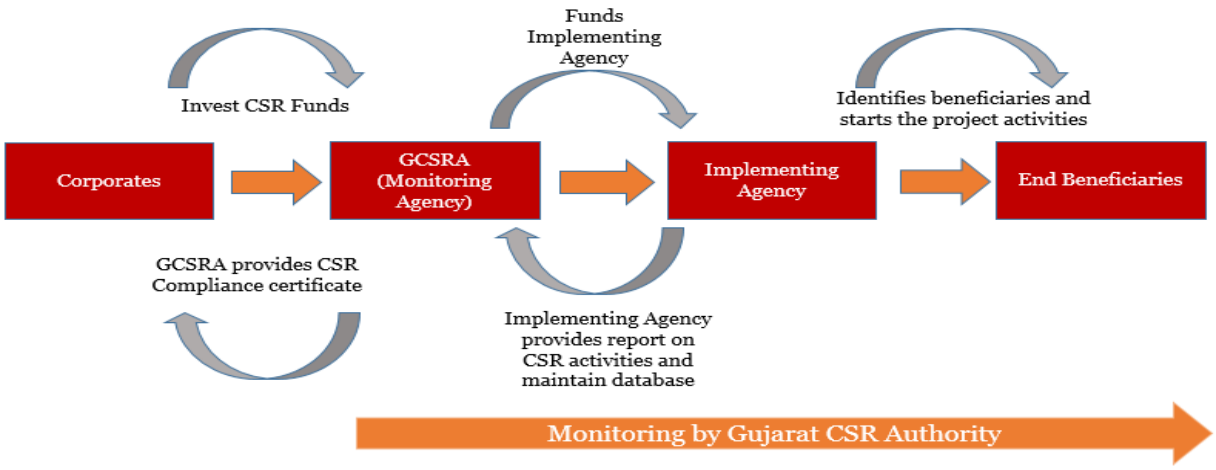
1. Stage 1: PLANNING

- Identification of the macro-geography where corporate is inclined to fund.
- Gujarat CSR Authority identifies local implementing agency for implementation.

- The identified agency would then be engaged by GCSRA to plan out the phase wise implementation of project at different locations across Gujarat.
- Initially one year of pilot project can be implemented in a particular district and based on the experiences can be up-scaled for a period of 2-5 years.

2. *Stage 2: IMPLEMENTATION*

Figure 1: Implementation Model



- Implementing agency shall approach the academic institutes to target the student population. They would also reach out to the rural communities, by targeting the social gatherings where people generally meet (at the common locations). Involvement of locally relevant institutions such as the Gram Panchayat, schools, hospitals etc. will help in spreading the word about the Thalassemia screening camps and awareness sessions.
- Post identification of the location, the agency shall organize a general awareness lecture regarding Thalassemia.
- Implementing agency would share the plan of screening test to be organized at different locations for prevention of thalassemia major child birth through comprehensive & structured awareness campaigns among college students and shall conduct High Performance Liquid Chromatography (HPLC) screening tests.
- The agency shall provide post-test counselling facility (in case of result is detected to be positive).
- Periodic visits by the GCSRA team to review the project progress

Stage 3: MONITORING & REPORTING

- Implementing agency will perform as per the project execution plan and update GCSRA on the progress of activities on a monthly basis.
- The agency shall provide GCSRA with a report on the CSR activities.
- GCSRA to then undertake an impact assessment study after 1 year of the completion of the project.

List of Success Indicators

Project outputs

- No. of people who have successfully undergone screening test
- No. of pre-marital groups sensitized towards prevention and control of thalassemia

- No. of Public lectures/talks/seminars etc. done to create awareness among the youth

Desired Outcomes

- Increased awareness among the youth about the prevention of Thalassemia and early screening before marriage
- Improved health for the next generation children of newly married or youth of the society

Potential Impact

- Reduction of incidence of thalassemia.

B. Implementing agency

The Project shall be implemented by GCSRA as a monitoring agency, with support from NGO or implementing agency being tasked with the responsibility of grass root implementation.

Roles and responsibilities

- **GCSRA**: Advisory and monitoring agency of the CSR activities i.e. strategic plan for the project, coordination between donors, technical service providers, monitoring & evaluation, documentation and (physical/financial) reporting for the Project, issues compliance certificate for the CSR activities.
- **Implementing Agency**: Baseline survey, Implementation support and reporting of CSR activities under the project.
- **Corporates**: funding support

C. Partnerships

The project shall be implemented, with funding support of corporates, in partnership with government at local/district/state level, Municipal Corporation, academic institutions, universities and colleges.

- ***Government Institutions***: Health and Family Welfare Department (National Health Mission)
- ***NGOs/Civil Society****:* NGOs working in the respective districts in the health sector
- ***GCSRA*** will be the monitoring partner for the project

D. Anticipated benefits from the Project

- Increased awareness on the latest developments, skills, knowhow and training for prevention of blood related diseases in state.
- Increased empowerment of community members to spread the word of mouth about the thalassemia screening test among the community which shall help in sensitize the larger section of youth of the society to get their thalassemia screening done.

Work plan

#	Activity Description	Q1	Q2	Q3	Q4
1	On boarding of NGO/implementing agency				
2	Screening plan and identification of location for Screening				
3	Public lectures/talks/seminars in educational institutions and other community gathering locations.				
4	Counselling of target audience before screening				
5	Testing through High Performance Liquid Chromatography (HPLC)				
6	Genetic counselling and family screening				
7	Monitoring of CSR activities by GCSRA				
8	Reporting				
9	Impact Assessment				

Estimated Financial Costs

The Project shall be implemented in a phased manner. The expected number of screenings in a year is 5,000. It shall further be divided into four quarters and in each quarter approximately 1,000-1,500 screening tests shall be done.

The estimated cost of thalassemia screening test for 5,000 patients is Rs. 25,00,000 /-, which is to be borne by the funding partner to ensure free of cost screening test for eligible youth. Assumptions are that quarterly there would be 4 awareness sessions conducted, i.e.in each quarter 1,000-1,500 blood screening test.

Table 4: Action plan for 5,000 blood screening test

#	Particulars	Q1	Q2	Q3	Q4	Total
1	Awareness Lectures & Pre-test Counselling	4	4	4	4	16
2	Target Testing	1,250	1,250	1,250	1,250	5,000
3	Post-Test Counselling	4	4	4	4	16

Table 5: Estimated cost for Screening of 5000 person

Sr. No.	Particulars	Unit cost (in INR)	Total Cost (in INR)
1.	Screening of 5,000 patients	500	25,00,000
2.	GCSRA Administrative Cost	@4% on total cost	1,00,000
	Total Project Cost		***26,00,000/-***

Table 6: Breakup of Rs. 500/- for Thalassemia screening test of one person[7]

#	Items	Cost (in INR)
1.	HPLC- Kit	249.00
2.	CBC- Kit	39.60
3.	Vacuette EDTA	1.94
4.	Syringe (6 ml)	5.00
5.	Sprit Swab	0.10
6.	IEC materials	2.15
7.	Software Records	10.00
8.	Receipt Book	0.30
9.	Forms for registration	0.10
10.	Administrative (Equipment, Vehicle maintenance & repair, depreciation etc.)	93.00
11.	Sample Storage / Electricity	6.00
12.	Staff Expenses	79.00
13.	Fuel for Camp Vehicle	10.00
14.	Report	2.00
15.	Miscellaneous	1.50
16.	Bio Med Waste	0.60
	Total screening cost per person	**500.29**

Monitoring

- GCSRA will act as the advisory and monitoring agency for the CSR project implementation and ensure compliance as per requirements, and will issue CSR compliance certificate to company against the investment made.
- Based upon the progress of the year, GCSRA will provide support to the company to develop a success framework, under which, performance indicators shall be defined and the baseline levels as well as targets defined over a 2-5 year horizon, on an annual basis.
- GCSRA will also conduct evaluation and impact assessment of the projects.

Reporting

The implementing agency would be responsible for the following:

- ensure the implementation of project as per proposed plan.
- ensure reporting on CSR activities to GCSRA on quarterly, half-yearly
- and annual basis as against the funds disbursed to them.

[7] *Reference: Indian Medical Science Research Foundation*