Report for Global Giving
Maharashtra Arogya Mandal

About the institute:-

Maharashtra Arogya Mandal Hadapsar, Pune, popularly known as MAM, is charitable trust established on 11th June 1960 by the Late Dr S.T. alias Dada Gujar and his colleagues with the aim to provide better health care facilities to the poor and underprivileged classes of society. This was the small beginning of "Maharashtra Arogya Mandal". The work that started with a small OPD, has now acquired a multifarious structure.

Maharashtra Arogya Mandal is involved in **health services**, **preventive medicine**, but instead of restricting to these areas, we also realized the need to work in support areas like **waste water, sewage disposal and sanitation, school children health monitoring and nutrition.**

- MAM is a Non Government and not for profit organisation.
- MAM is a registered charitable trust under society's registration Act 1860 (F-230 (Poona) of 5th April 1961) and under Bombay Public Trust Act 1950.
- The donations are exempted under section 80 G of Income Tax Act.
- We have FCRA registration to receive foreign donations, details as under -
  FCRA # 083930071 / dated. 5th March 1985**.**

Aims and objectives

- To educate people about **health care, sanitation** & the advantages of **small family** and to create awareness amongst people for **social & economical upliftment.**
- To build up a community of villages by providing equal rights to women on the firm pillars of justice, **equality** and love.
- To educate people to eradicate social evils such as dowry**, untouchability** etc.
- To enhance livelihood conditions of tribal community by creating avenues for increasing income based on local resources**.**

Functional Areas : Rural & Tribal Development, Medical / Health, Education

There are **15 different Institutes** functioning under the roof of MAM in the above streams. The institutes are running various projects in the all these functional areas focusing on tribal and rural region.

Work review: - Health Sector

About Sane Guruji Arogya Kendra (SGAK): Since **11 June 1960**

It was the enormous efforts of the principal founder member Late **Dr. Dada Gujar** and his colleagues Dr. Baba Adhav, Dr. Gopal Shah, Dr.Martand Patil, Dr. Sindhu Ketkar who brought this institute to current glory. They all together started "Sane Guruji Rugnalaya" with just 4 beds on 11th June 1960 in rented premises. Subsequently, a **Public Chartable Trust** called **Maharashtra Arogya Mandal** was registered on 5th April 1961 of which Rugnalaya **(Hospital)** is the **main unit. In few years the hospital earned a reputation for efficiency and for its concern for the poor.** 4 doctors from the group have left MAM to work in the field of their choice and from 1965 onwards Shri.S.T.alias Dada Gujar took over the onerous responsibility and with a new team. Initially trust focused on health services however the trust had to widen its scope of activity from **health to education**.

Once started with **a 4 bedded hospital in rented building**, the Maharashtra Arogya Mandal is now the owner of 250 **bedded Charitable Trust hospital** with following facilities at a very minimum cost..

Facilities:

- Intensive Care Unit.
- Physiotherapy Unit.
- Well equipped Pathology Laboratory
- 24 hrs emergency services
- Mother and Child Welfare Centre and NICU
- AIDS Counseling Centre (ICTC)
- District TB Centre
- Full fledged state of the Art Panchakarma unit.
- Well equipped State of Art Operation Theatre
- Radiology Dept. - X-Ray, Sonography, E.C.G., 2-D Eco & Color Doppler

Sane Guruji Arogya Kendra **treats more than 12,000** inpatients and **one lac** out patients (OPD) annually, with in-house staff, all up-to-date facilities and active association of Honoraries renowned in their field of specialization**. It is remarkable that the quality of medi-care being comparable with any other modern hospital,** poor patients receive treatment either **free or at a substantial concessional rate.**

SICKLE CELL ANAEMIA PROJECT-A REVIEW -since 1998

Roshmal Bk. Tal Dhadgaon Dist. Nandurbar

Introduction

In addition to hospital with all modern facilities started in the Hadapsar area of Pune city, several health projects catering to the needs of tribal people in rural areas were also developed. The Sickle Cell Anaemia Project is such a project that started in 1998 **with a mandate to provide diagnosis, treatment, counseling and prevention.**

About Sickle cell Anaemia

Sickle cell anaemia is a genetic (hereditary) defect confined to red blood cells with no definite cure. The basic defect is in the structure of hemoglobin molecule of the red blood cells. These cells acquired sickle like shape in oxygen deficient environment. Due to this effect there is early destruction of the RBC (red blood cells) leading to condition known as **Sickle Cell Anaemia**.
The individual with sickle cell anaemia has common symptoms

- **Moderate to severe Anaemia**
- **Mild Jaundice**
- **Severe joint pains**

In addition to these symptoms one of the typical symptoms experienced by majority of the patients is known as **Sickle Cell Crisis**. Whenever there is increase demand for oxygen in the body i.e. during infections, after heavy physical work out, when exposed **to extreme cold or hot summer** or excess fluid loss (due to diarrhea or vomiting) , the **Sickling process gets accelerated**. The sickled red cells entangle with each other and cause obstruction in micro-capillaries leading to tremendous pain at that site. The frequency, period, intensity of crisis varies from individual to individual. When, where, how crisis develop is difficult to predict. Pain remains for few hours to few days. During crisis, pain is unbearable and analgesic drugs have limited effect.
The patients have a painful and limited life span. It is observed that patients have less immunity and hence more susceptible for common infections. With the chronic illness and repeated episodes of crisis every organ of the body is likely to be affected with varied disorders like **brain with stroke (paralysis), the lungs with respiratory failure, the kidney with renal failure and Avascular necrosis of bones**.

The long-term studies emerge out following observations.

- **It injures every organ of the body but does not affect everyone in the same way.**
- **Differ in both extent of complications and severity from individual to individual.**

Genetics of Sickle Cell Hemoglobin

In a population the defect occurs in two forms, one **heterozygous state** (suggesting defect on only one chromosome of the pair) and another **homozygous state** (suggesting defect of both chromosome of the pair). Heterozygote individual usually do not suffer from any symptoms of the disease and hence known as **carrier** and homozygote individual always remain ill and known as **sufferer.** In depth studies of sickle cell defect suggest following guidelines.

- **The parents of sufferer baby are always carrier or sufferer.**
- **To a carrier parents the chance to have sufferer baby at each pregnancy is 25% carrier baby 50% and baby without sickle cell defect is 25%.**
- **In affected population the ratio of sufferer to carrier is 1:20**

Health problems amongst S.T. (tribal), S.C. & OBC population from these areas have been studied by MAM which are as follows –

- Malnutrition and Water borne and communicable diseases
- Genetic Disorders like Sickle Cell Anaemia, Thalassemia
- Consumption of alcohol, Superstitions, Extreme poverty, Inadequate health facilities

Rationale for selection of Dhadgaon Taluka (Block) for our community control programme.

- Difficult hilly terrain located between third, fourth, and fifth and sixth ranges of Satpuda. 96% population belongs to tribal population groups. Tribal population remains backward, isolated from rest of the district. Medical facilities (including preventive) are inadequate and poor in qualities.
- Sickle cell disease is one of the public health problems in this area.

Maharashtra Arogya Mandal, Pune is voluntary heath organization having vast experience of working in tribal areas, expertise knowledge about genetic disorder (prevalent in tribal areas), a team of devoted medical and non –medical staff. We are working in this tahsil since 1998 and screened 25 villages for sickle cell disorder and other health problems. We found high prevalence for nutritional anaemia and sickle cell anaemia. We have **laboratory and facilities for blood investigations**. We have conducted population screenings programme in 20 villages from this Taluka for sickle cell disorder.

On the basis of data collected by our team the rough estimation for sickle cell disorder is as follows.

- **Total tribal population of Dhadgaon Taluka**
  (As per 2011 figures) - 1, 95,343
- **Estimated carrier individuals**
  (Prevalence 22.5%) > 43,000
- **Estimated sufferer individuals**
  (Prevalence 1.2%) > 1900

Prevalence with Screened Data as per 2011 figures.

Total population of Nandurbar Dist.	**> 16,77,179**
Expected carrier (approx 22.5%)	**> 3,70,389**
Expected sufferer (approx 1%)	**> 16,500**
Total population Screened till date	**1,25,789**
Carriers (22.5% approx)	**28,919**
Sufferers (1% approx)	**1360**

Team of Maharashtra Arogya Mandal lead by Dr.S.L.Kate (Ph.D Medical Genetics) by have been working in this district for last several years and found that approx. 22%of the tribal people are carriers for the disorder and approx 1% people are sufferers.

It was noticed that even though Sickle cell anaemia is public health problem, people have no idea about Sickle cell disease. **Consequently Maharashtra Arogya Mandal has decided to work on Sickle Cell Anaemia Problem and established a community control center popularly known as "Sickle cell Dawakhana" at Roshmal BK, Dhadgaon taluka.**

In our centre which is popularly known as we provide following facilities.

- **Diagnostic facilities for sickle cell disorder.**
- **Treatment and follow-up of patients.**
- **Population genetic screening program to detect carriers and sufferers.**
- **Health education**
- **Marriage counseling / Genetic counseling**
- **Guidance for Pre natal diagnostic facilities.**
- **Training facilities.**
- **Improvement in quality of life of sickle cell sufferers.**

As this disease has no definite cure prevention part plays an important role in which pre marriage counseling is most important. If the patients and carrier parents agree than it is possible to avoid birth of new sickle cell child.

On the basis of our experience we have developed a **Sickle cell medical kit** which consists of a polyherbal medicine called **SC3, Folic Acid, Soda mint and Painkillers like Paracetamol. This kit is distributed free of cost.**
We have **1360 patients** diagnosed out of which (approximately) **700** are under regular medical supervision. Every time our old patient brings new patients from his/her village. We organize our health camps bimonthly and by finding out responses of the patients. We provide all facilities like counseling, possible treatment **free of cost**.

Details of Camps conducted in December 2011.

MAM has conducted free sickle cell health check up camp in 24th December 2011 from of 26th December 2011. During the journey we had a check up of **4** old diagnosed sickle cell patients at Dhule Highway. On Sunday **25th** December 2011 **293** old diagnosed sickle cell patients were clinically examined and were given free medications. Also screening of new **83** patients was done among which **41** were diagnosed as carriers and **28** patients were identified as sufferers. Advice and counselling regarding the dietary and behavioral regime was also given both old and new patients. The carriers

were provided with counselling emphasis was given on premarital guidance specifically to unmarried individuals. **14** individuals were diagnosed as normal which were also guided for this social problem. All the individuals were from different tribal parts of Nandurbar district mostly from low socio economic class.

On 26th Dec. 2011 similarly **251** old patients had undergone medical check up and **47** new patients were screened for sickle cell disease. In Newly screened patients **9 patients** were diagnosed as sufferers and **26** were diagnosed as carriers. **12** individuals were diagnosed as normal. Premarital counselling, guidance regarding the behavioral and dietary regime was given to the patients. Counselling was given to carrier patients. The Normal people were also guided regarding the prevention of this disease. In this camp one sufferer patient of CTEV (congenital talipes equinovarus) commonly known as clubbed foot was observed.
Looking at the intense cold climate in the project area during this camp the cloths and **50 sweaters were distributed free** to needy sickle cell patients.

Sickle cell health check up camp – December 2011

Sr. No	Date	Place	Old patients	New patients Screened	A+A	A+S	S+S
1	24/12/2011	Dhule	4	-	-	-	-
2	25 /12/2011	Dhadgaon	293	83	14	41	28
3	26 /12/2011	Dhadgaon	251	47	12	26	9
Total	678	-	548	130	26	67	37
Total patients :- (548 + 37 Patients)							

The only way to control this disease is to avoid the birth of new sickle cell child hence importance of premarital counselling and diagnosis was explained. **Some local tribal volunteers also support to translate the information about marriage counselling in local tribal language.**

We feel that the key of success of any project depends on the cooperation of patients and dedicated team work. Patients and parents are happy with our medical and social treatment.
Though there is a known prevalence of sickle cell disease in this area as approximately 1% in our every health check up camps **we find the sufferers more than 25 % in every screening.** Every patient who is aware of symptoms and is benefited by our treatment, he identifies similar symptoms of another tribal person and carries him from his hamlet to our community control centre (Sickle Cell Dawakhana).
At present the project is running without any financial support.

Appeal: - Need of Vehicle

- It is a difficult hilly terrain located between 3rd to 6th ranges of Satpuda this is more than 550 kms from Pune (headquarter) where 96% population belongs to tribal population groups which is isolated from rest of the district.
- Bimonthly Sickle Cell diagnostic and treatment camps are organized in which 12-15 Medical and paramedical Staff along with Laboratory equipments, Generator, Medicines has to travel constantly for more than 16 hours.
- We also have a checkup of some identified diagnosed patients near Dhule during the journey.
- We have to carry the instruments, emergency and routine medicines as well as cloths for free distribution.
- The present vehicle which we are using is more than 15 years old.
- We require a sponsor, donations for 20 +1 seater vehicle.

Appeal for individual donors:

- In the Sickle Cell disease the iron tonics are not indicated as they may result iron overload. In this situation we have to emphasis on nutritious natural food ingredients which are iron rich. We also require support for nutritional supplementation as the tribal are very poor and cannot afford nutritious food supplements.
- Behavioural regime plays an important role as if the patients are provided with warm accessories, blankets, umbrellas, Sweaters, Hot water bags etc. They can be get protection in extreme cold environment which will avoid the Sickle cell crisis (Unbearable Joint pains). We require support from you for such Medico Social cause.
- Medicines and the expenses for approx. 500 patients in each camp are borne by MAM we require support from you to sponsor a medical health check up camp.
- We also plan to make a partial shelter in front of our Sickle Cell Dawakhana we require a sponsor for this it is a need because it will give shade and protection during summer and rainy seasons.
- Electricity cut off is common in rural and tribal area. As we work in tribal area we plan to set a solar panel which will be helpful in summer and winter (7-8 months in a year) to generate electricity as the blood test carried out for sickle cell diagnosis require electricity. Donors are requested to help for this social cause.

Expression of our patients

I am a sickle cell sufferer and combating with this disease. Due to this disease I was suffering from Avascular Necrosis of Femur Head. MAM supported me to overcome permanent disability by helping for Total Hip Replacement. I am now able to perform routine activities and also take part in the camps conducted by MAM. - Manoj Pawara, A sickle cell patient

We thank to our individual and institutional donors who helped us morally and financially in the past particularly Arbeiterwohlfahrt International Germany and CCRAS, Dept. of AYUSH, Govt. of India.

Thanks and Regards

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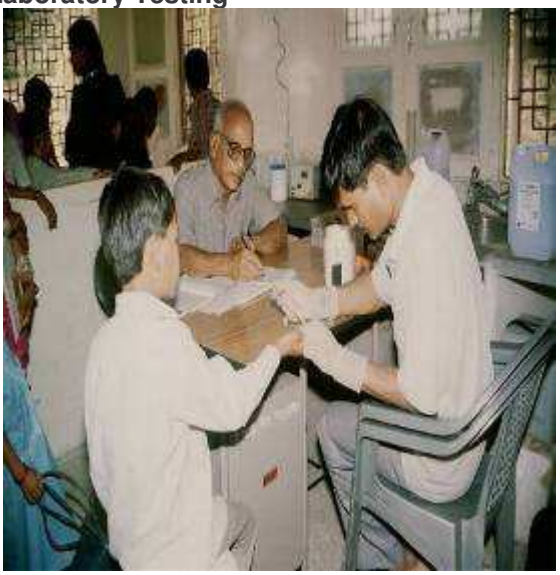
Visit of International Sickle Cell Scientist to Sickle Cell Center Dhadgaon, Dist. Nandurbar
Dr.Serjeant felicitated by Dr.Dada Gujar

Laboratory Testing



Instructions:-How to use Hot water Bags

Distribution of Blankets and Warm clothing

Lectures Regarding Awareness, Guidance and Counselling

Sickle cell Patient Mr. Manoj Pawara participating in camp activities

Clinical Examination **Maintenance of health records**