



**ANNUAL REPORT FOR THE CLEFT PROJECT OF AGAPE TRUST FROM ST THOMAS CLEFT
CENTRE FOR THE YEAR 2012-2013**

DR MATHEW PC

PROJECT DIRECTOR

ST THOMAS CLEFT CENTRE, KERALA



St Thomas Cleft Centre Funded & Supported by

CLEFT-CHILDREN INTERNATIONAL CCI

Founder, Prof. Dr., Dr. med. dent., Dr. h.c. mult. Hermann F. Sailer

CONTENTS

1. INTRODUCTION

2. INAUGRATION REPORT

3. CAMP REPORT

4. CASE STATISTICS

5. FELLOWSHIP PROGRAMME

6. FUTURE PLANS

INTRODUCTION

The Indian sub-continent remains one of the most populous areas of the world with an estimated population of 1.1 billion . This yields an estimated 24.5 million births per year and the birth prevalence of clefts is somewhere between 27,000 and 33,000 clefts per year. Inequalities exist, both in access to and quality of cleft care with distinct differences in urban versus rural access and over the years the accumulation of unrepaired clefts of the lip and palate make this a significant health care problem in India. In recent years the situation has been significantly improved through the intervention of Non-Governmental Organisations participating in primary surgical repair programmes. The cause of clefts is multi factorial with both genetic and environmental input and intensive research efforts have yielded significant advances in recent years facilitated by molecular technologies in the genetic field. In 2008, the World Health Organisation (WHO) has recognised that non-communicable diseases, including birth defects cause significant infant mortality and childhood morbidity and have included cleft lip and palate in their Global Burden of Disease (GBD) initiative. It is estimated that the overall global prevalence of orofacial clefting is one affected individual in every 600 new born babies. Assuming 15,000 births per hour worldwide (US Bureau of the Census, 2001), a child is born with a cleft somewhere in the world approximately every two minutes. Despite efforts to record the frequency of birth defects over the years, accurate data on the epidemiology do not exist in many countries. Craniofacial anomalies and cleft lip and palate in India based on the last study which was most rigorously conducted, the number of infants born every year with cleft lip and palate is 28,600, which means 78 affected infants are born every day, or 3 infants with clefts born every hour.

With the existing scenario prevailing in India as being mentioned in the incidence of cleft cases, it is imperative to start a centre with multi-disciplinary approach to treat cleft and craniofacial diseases. To look in to the various centres in India especially Kerala only few centres are providing care for these cases. Requirement for more centres is being recommended to treat not only for the primary but also the secondary problems associated with these cases. A baby born with cleft lip and palate many have to pass through various stage of surgical and dental intervention. A centre established in all these area of treatment of cleft is lacking in the state of Kerala. Many cases of cleft are from extreme rural areas. These people have to be informed through camps, the message have to be taken to them. The existing centre in Kerala are concentrated in only developed towns, making it difficult for many cases to travel and stay .Preventive education in relation cleft is lacking which is the primary target of responsible cleft team members.

The year of 2012 was a fruitful year for AGAPE Trust in association with St Thomas Hospital .It was the year when the vision of the Trust in starting a charity based organisation was being organised and sent for acceptance to Cleft Children International (CCI) for a Cleft and Craniofacialcentre. Based on the Proposal letter representatives from CCI visited the Hospital and checked the facilities available as per CCI protocol .Based on their suggestion CCI announced to start a centre of excellence in treating cleft and craniofacial anomalies to serve the needy and the Poor children's for the state of Kerala. **This centre is the only centre to provide comprehensive cleft treatment completely free of cost to the poorest of the poor.**

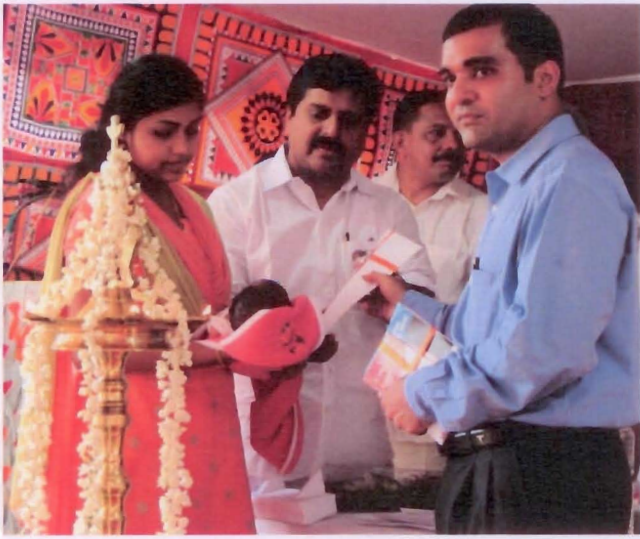
Plans are there to make this centre as the primary referral centre for any craniofacial cases. In India centres doing Distraction osteogenesis which is a mode of advanced surgical management for these cleft cases is being performed in a few number , this project plans to start a centre of advanced management for secondary cleft cases including distraction osteogenesis. Project plans to give patients free food and transportation charges. It also proposes to conduct regular craniofacial workshops, meetings of the NGO association for the betterment of the organisation and for transfer of information. Project also plans to introduce research in the field of cleft and craniofacial cases including genetic analysis, cleft palate correction with distraction, and many other advanced innovative techniques to make this centre as an area of expertise in treating cleft and craniofacial cases

INAUGURATION REPORT

On October 2012 AGAPE in association with ST Thomas hospital organised a grant inauguration attended by many dignitaries from the Kerala government as well as from the local authorities. Representing from the government include Health minister, Member of Parliament and municipal chairperson. The inauguration was addressed by **PROF: SAILER** by means of video transmission from Switzerland where PROFESSOR explained the work performed by CCI and the vision of CCI. Health minister officially inaugurated the centre and congratulated CCI and the hospital in starting such a centre of excellence in providing care to the needy and poor children's of the society. Hospital submitted a proposal letter to the government in recognising this centre as the centre of excellence by the government and to start a cleft data base registry. During the function the first five cleft childrens were officially admitted in to the cleft centre by the minister. Release of cleft information booklet was done. Cleft office inauguration was done by the member of parliament.



INAUGURATION BY THE HEALTH MINISTER



INAUGURATION EVENTS PHOTOS

CAMP REPORT

The hospital from the first day itself believed that for any centre to perform better it requires the help of NGOs in conducting camp and providing patients. We were in constant touch with many NGOs .With many NGO we were able to conduct more than 23 camps till now providing more than 200 cases to the centre.Through the various camps the purpose of eliminating the cleft scenario is also being undertaken by the Trust.

Alappuzha Camp at ST THOMAS HOSPITAL





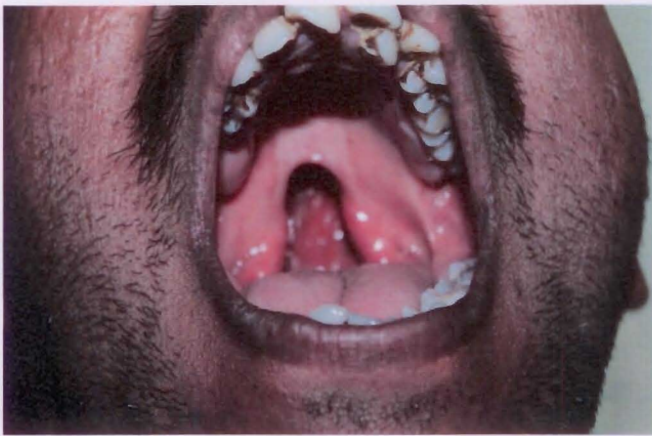
AMBALAPUZHA CAMP

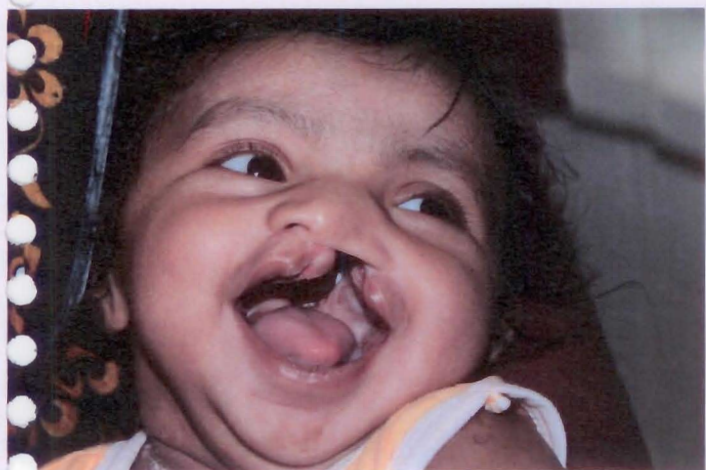


CAMP AT CALICUT

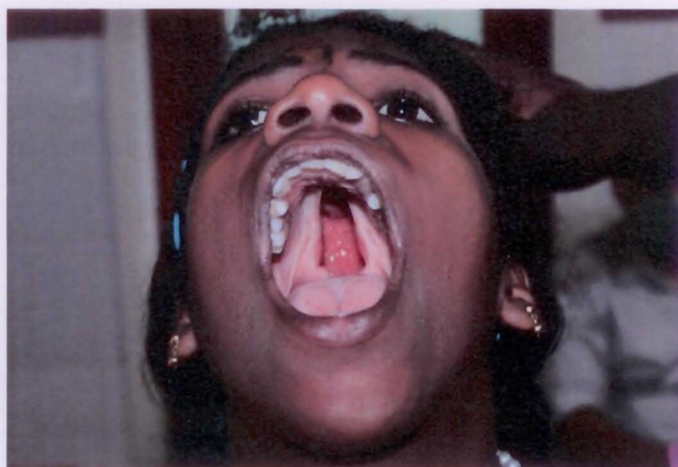


HOPE TRUST CAMP



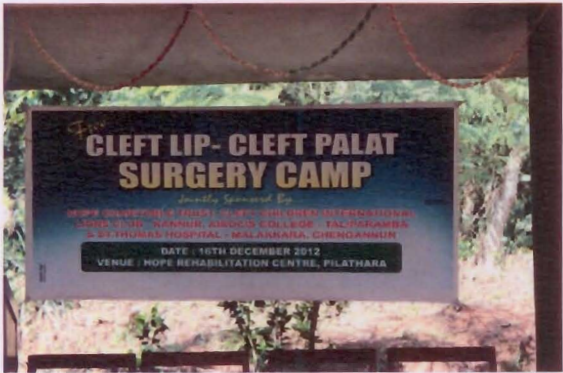


ICDS CAMP ST THOMAS HOSPITAL

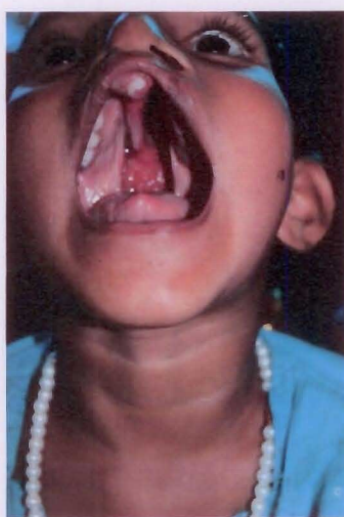
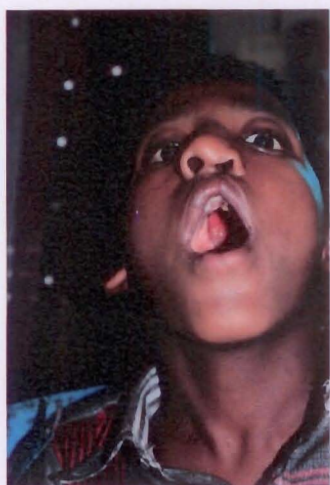




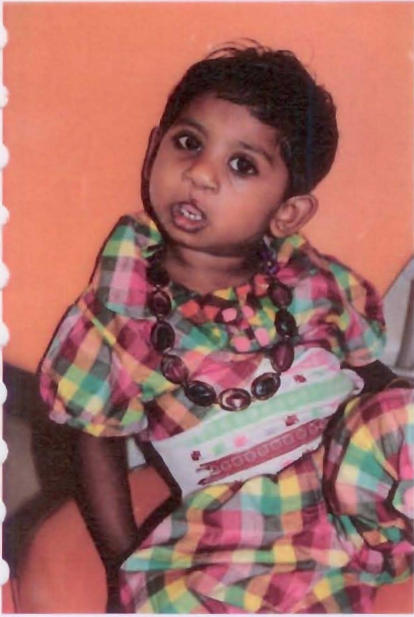
KANNUR CAMP



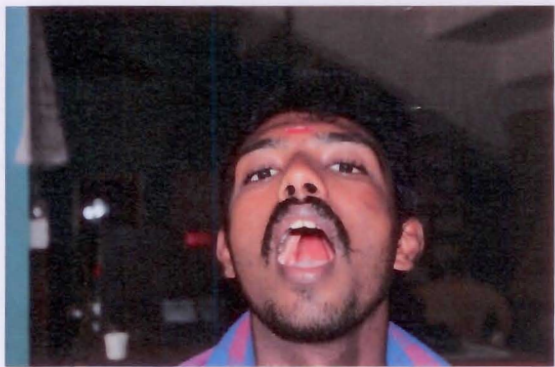
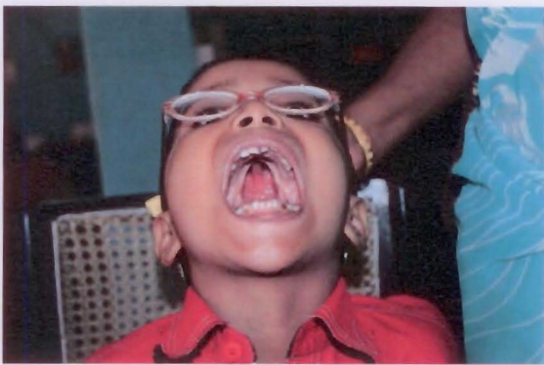
KOLLAM CAMP HOPE SOCIETY



KOLLAM CAMP DR JAYANTHS CLINIC



KOLLAM ICDS CAMP



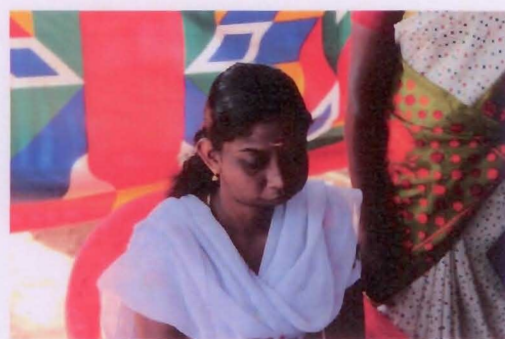
KOTTAYAM CAMP



MALAPURAM CAMP



PALAKAD CAMP



AGAPE TRUST CLEFT TEAM VISIT TO HOPE REHABILITATION CENTRE



CAMP INAUGURATION BY CIRCLE INSPECTOR OF POLICE
KOZHIKODE



NEWS PAPER ARTICLE ABOUT THE CENTRE



It was of immense pleasure that patient from Kanpur was identified by our health worker. The baby was operated here in the centre and they were given a grand send off by the hospital staff. The Trust along with Hospital staff visited the HOPE rehabilitation centre at Kannur. Indian dental association Tiruvalla chapter took the initiative to collaborate with the centre to promote the awareness among the state in prevention of cleft scenarios.

At present the Trust have conducted camps from Trivandrum to almost Kasargod touching almost all the district of kerala.

Letter of Government Support for the Centre

"ഭരണഭാഷ - മാതൃഭാഷ"

നം.ഐസിഡിഎസ്/ബി 2-3571/13

സാമൂഹ്യനീതി ഡയറക്ടറേറ്റ് (അനക്സ്),
സാമൂഹ്യക്ഷേമ ഭവൻ, പൂജപ്പുര,
തിരുവനന്തപുരം. തീയതി : 10-7-2013

സാമൂഹ്യനീതി ഡയറക്ടർ.

Dr. A. ചെറിയാൻ
St. തോമസ് ഹോസ്പിറ്റൽ,
Cleft & Craniofacial Centre,
Malakkara-P.O,
Pathanamthitta District,
Pin - 689 532

സർ,

വിഷയം : സാമൂഹ്യനീതി വകുപ്പ് - Cleft Children International -
ജന്മനാ വൈകല്യമുള്ള കുട്ടികൾക്ക് സൗജന്യ ശസ്ത്രക്രിയ
- സംബന്ധിച്ച്.

സ്വചന : സർക്കാർ കത്ത് നം. 176/എ2/2013/സാനിവ തീയതി
11-12-13.

ജന്മനാ വൈകല്യമുള്ള (മുച്ചിരി, മുറി അണ്ണാക്ക്) കുട്ടികൾക്ക് സൗജന്യ
ശസ്ത്രക്രിയ നടത്തുന്നതിലേയ്ക്കായി വിവിധ ജില്ലകളിൽ നിന്നും ലഭ്യമായിട്ടുള്ള
അപേക്ഷകരുടെ പേരു വിവരം അനന്തര നടപടികൾക്കായി ഇതോടൊപ്പം ഉള്ളടക്കം
ചെയ്യുന്നു.

വിശ്വസ്തതയോടെ

സാമൂഹ്യനീതി ഡയറക്ടർ

ജികെ/



We also planned to do media propagation by means of radio transmission. The centre signed anMoU with FM station in conducting regular talk shows about cleft and also to propagate and educate the society about cleft and the services rendered by the centre to the society.



MoU SIGNED WITH RADIO STATION

FELLOWSHIP PROGRAMME

As a part of continuing education programme the centre started a Two Year Fellowship Programme in cleft and craniofacial surgery. A paper advertisement was placed and candidates were chosen by the centre and sent to CCI for acceptance. Dr Balaji Shenoy was selected to be the Fellow for 2013-2015. The fellowship programme includes intense training in the field of cleft and craniofacial anomalies.



CASE STATISTICS

From November 2012 till present date almost 456 cases has being registered with the Trust for seeking treatment for cleft & craniofacial surgery. 326 cases has being operated in the centre. 23 camps has being conducted by the trust. Most of the cases are gathered through camps almost 95% are from various camps organised by the Trust. As a normal protocol all our cases selected for surgery must submit a copy of their Ration card for annual income, letter from the ward member for proof of identity and address.

FUTURE PLANS

- The centre is planning this year to start the cleft registry . Introduction of cleft registry in association with government so that when new cases are born it will be intimated in the hospital so that proper counselling and treatment could be provided
- We are planning to approach the railway ministry in helping us place the advertisement in railway stations. Proposal were given to the government in placing advertisement in government buses. Media propogation by means of Television programmes is also planned. Conduiting more camps in the rural parts of kerala through the help of government is also being initiated.
- Plans to build a separate block for cleft centre with dinning and play area with additional facilities such as library,kitchen for parents to cook the foods .
- Introduction Of Cleft Information Van Which Plans To Go Through Each District Of Kerala For Propogation Of Awarness And The Requirement Of Treatment

WOULD LIKE TO THANK ENTIRE TEAM OF CCI ESPECIALLY
PROF: DR SAILER & DR ERICA SCHWOB IN CONTINUING
SUPPORT FOR THIS CENTRE



St Thomas Cleft Centre Funded & Supported by

CLEFT-CHILDREN INTERNATIONAL CCI

Founder, Prof. Dr., Dr. med. dent., Dr. h.c. mult. Hermann F. Sailer



**ST THOMAS HOSPITAL
CLEFT & CRANIOFACIAL CENTRE
(A PROJECT OF AGAPE OUTREACH SOCIETY)**

FUNDING & SUPPORT BY



Prof. Dr., Dr. med. dent., Dr. h.c. mult. Hermann F. Sailer

CLEFT-CHILDREN INTERNATIONAL CCI