



MEENAKSHI
ACADEMY OF HIGHER EDUCATION & RESEARCH
DEEMED TO BE UNIVERSITY U/S 3 OF UGC ACT, 1956

BEST PRACTICE 2

Services offered for Generally Less Prioritised Diseases (GLPD) by Meenakshi Institute of Facial Aesthetics and Craniofacial Excellence (MI FACE)

Objectives / Goals:

- Identify diseases of low priority in the public healthcare system, create institutional systems to raise awareness, study, research and treat them.

The Context:

India's healthcare system is overburdened, underfunded, understaffed and unevenly distributed. While many diseases and conditions are well known and attract adequate medical, social, administrative and government attention, a few diseases that primarily affect the poor are largely overseen. Diseases like cleft lip and palate anomaly are predominately prevalent in rural areas where there is an acute lack of awareness and resources for multidisciplinary approach necessary for successful treatment. Many patients receive limited or suboptimal care. The existing public healthcare system is overburdened and prioritized to tackle important communicable and lifestyle diseases such as tuberculosis, AIDS, malnutrition based diseases, Malaria, Dengue, Diabetes, Hypertension, etc. Diseases such as cleft lip and palate is a common congenital deformity of the craniofacial region with an incidence of around 1 per 600-800 live births or higher in India and requires multidisciplinary treatment from birth until adulthood. The defect adversely affects not only speech and normal development of facial and oral functions, but due to disfigurement, becomes an impediment for participation in the society.

The Practice:

MAHER has identified a number of Generally Less Prioritised Diseases (GLPD) to focus on, based on the disease burden, availability of expertise, facilities and opportunities of treatment, as well as affordability. Orofacial clefting (OFC) is one such disease that describes a range of

abnormalities that manifest in the newborn infant involving structures around the oral cavity and facial structures resulting in oral, facial and craniofacial deformity.

- A multi- and trans-disciplinary team drawn from various constituent units of dentistry, medicine, allied health and nursing specialties was formed as early as in 2003 to create a unit for treatment of cleft and palate related anomalies.
- The unit and its program, as it gained experience, expertise, and sustained success, was upgraded with funds, dedicated staff, instruments, operating facilities and operational governance.
- In due course of time, referral networks were established for dentists, pediatricians, neonatologists, social workers and other healthcare professionals to refer newborn babies or children into the program.
- The unit was upgraded to a centre for cleft and palate diseases with enhanced funding as the number of treated patients increased.
- Speech therapy, facial aesthetics and other allied therapeutics were undertaken and the scope of this practice widened, necessitating the transformation of the centre into the Meenakshi Institute of Facial Aesthetics and Craniofacial Excellence (MI FACE).
- The Institute has conducted more than 58 seminars, conferences and workshops on the topic, sharing its expertise and training over 4800 dental surgeons, pedodontic surgeons, oral medicine dentists, nurses, social workers, ASHA workers, operating theatre technicians and other healthcare professionals in various aspects of craniofacial medicine.

The primary challenge in the treatment of OFC is that it requires collaboration and cooperation from a wide range of specialisation, beginning with pre-marriage genetic counselling, prenatal screening, obstetric care, neonatal management, pediatric surgery, investigations, etc etc. In India, absence of births defects registry leads to paucity of data. The secondary challenge in OFC is the lack of standardised protocol for standard of care and surgical treatment, since there is an acute lack of sound evidence base. OFC requires follow up care throughout childhood into adulthood. Maintaining continuity of care and tracking of families has always been a challenge.

At MI FACE, these challenges have been tackled through establishment of multidisciplinary teams, project management principles and innovative patient data management systems in

addition to evolving unique standard operating procedures and protocols, that are well documented, studied and improved upon. MI FACE today is a centre of excellence that serves as a sustainable model being replicated for other similar diseases in India and South Asia.

Evidence of Success:

At MI FACE, over 8000 patients have benefited from the sustained focus and attention on OFC.

The Centre drew international attention due to its high profile successes, and was approached by the ‘**Cleft Children International, Zurich, Switzerland**’ for collaboration in the year 2003. Till date, more than 10,000 patients have benefited.

Research into OFC at the institute has resulted in publication of over 1000 articles, scientific papers in various high impact factor journals. A textbook on OFC is ready for publication. The Institute is now recognised widely for its expertise in treatment of OFC and attracts patients from all over India, even from far eastern states of Assam and Tripura, which attests to the impact of the institute’s work on the disease.

Evidence of Success parameters:

Parameter	2017-18	2018-19	2019-20	2020-21	2021-22
Funding/ Donations received in INR lakhs	137.21	136.45	122.034	60.69	90.21
Patients benefitted- Cleft Surgeries	320	310	269	78	154
Patients benefitted- Craniofacial Surgeries	39	37	37	21	22
Doctors trained on Fellowship	2	2	2	2	2
Camps conducted (in Districts) [no.of patients]	6 (4) [94]	3 (3) [20]	-	-	-
Seminars / Workshops organized	-	2	-	-	1
Publications in the specialization	5	7	5	3	5

Problems encountered and resources required:

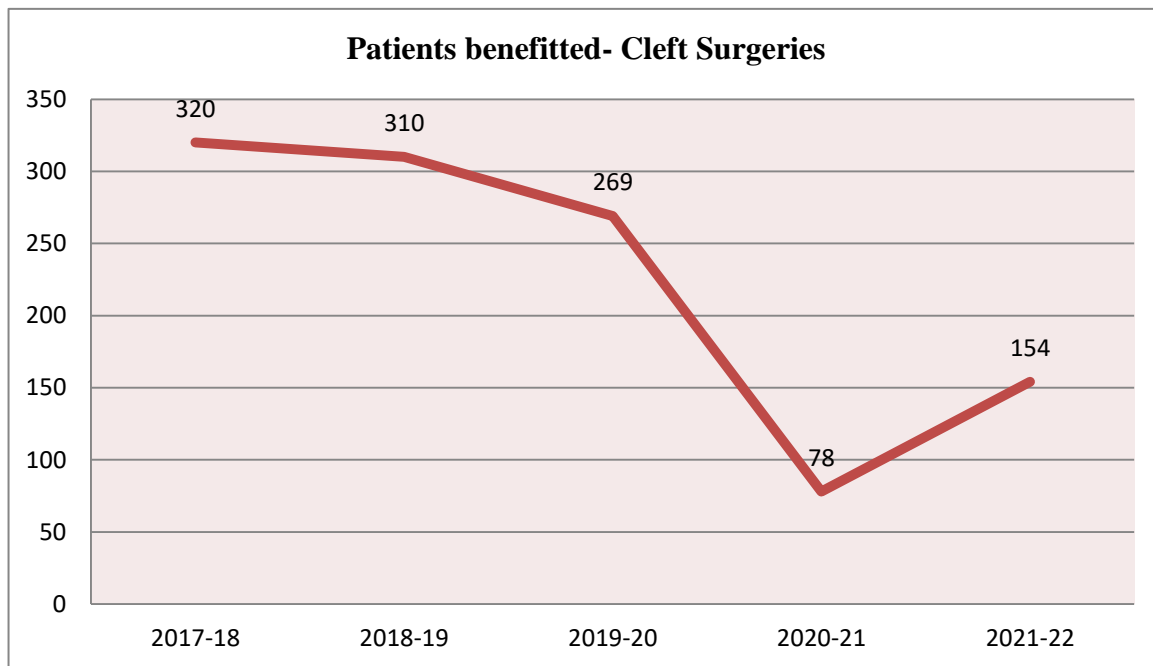
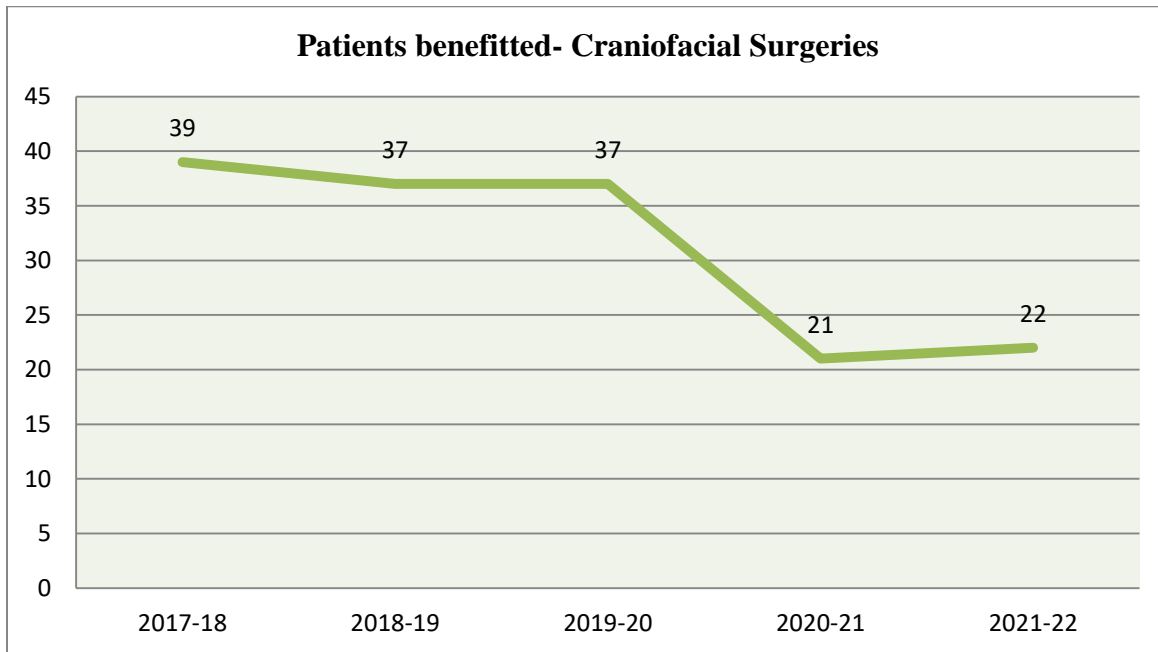
Problem 1: Department & Speciality Silos exist in most Institutions and diseases that require multidisciplinary approaches need special planning and management. The problem is exacerbated when teams from hospitals that are geographically far are required to work together. Logistics of meetings, procedures and time management need easy and simple solutions.

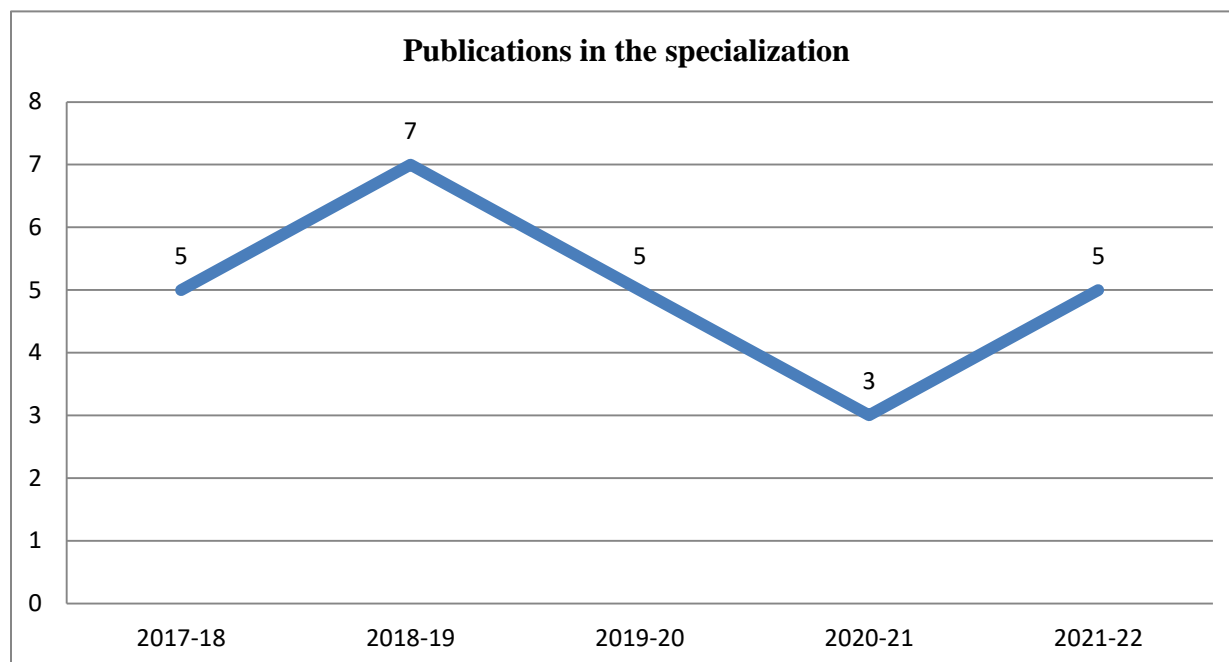
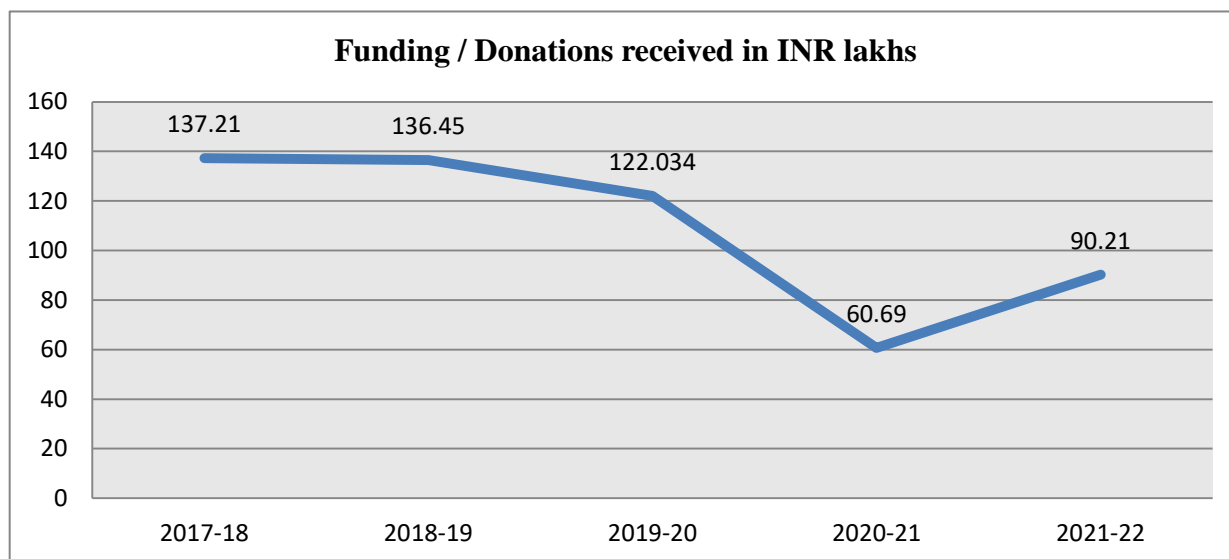
Solution 1: Project management principles were studied and employed to evolve a methodology for planning regular and on-demand meetings either in person or by virtual conferences (even before virtual meetings became standard during the COVID pandemic). Patient data, medical history and records were digitized for easy sharing among the multidisciplinary team. Planning for procedures were optimized with the use of checklists and standardized forms.

Problem 2: Follow up of Patients was a challenge since most of them were poor and lacked permanent addresses, and were prone to migrate for work and other economic reasons. OFC required regular follow up visits, corrections and management to ensure optimal and successful outcomes.

Solution 2: The Humane Touch: MI FACE engaged dedicated and well trained social workers who would take personal interest in the patients and keep in regular touch with the parents. The patients and parents were treated with extra sensitivity, counselling, motivation, psychological assistance, advice, help in planning, etc. The sum total of all these personal relationships are what we call the Humane Touch that helped us trace, keep in touch and bring the patients back for continued care towards success.

ANALYSIS OF CLEFT PARAMETERS 2017-22





Notes:

Meenakshi Cleft and Craniofacial Centre

Alapakkam Main Road, Maduravoyal, Chennai -600095.

Number of Patients Treated From January 2017 to December 2022

S.No.	YEAR	CLEFT CASES	CRANIOFACIAL CASES	ORTHODONTIC CASES	TOTAL
15	2017	320	39	35	394
16	2018	310	37	59	406
17	2019	269	37	39	345
18	2020	78	21	9	108
19	2021	154	24	27	205
20	2022	186	31	47	264
		1317	189	216	1722

Photo Gallery:



Cleft Lip & Palate Screening Camp at – Prakasam Dist.



Cleft Lip & Palate Screening Camp at – Chittoor Dist.



Cleft Lip & Palate Screening Camp at – Chittoor Dist.



Cleft Lip & Palate Screening Camp at – Chittoor Dist.



Cleft Lip & Palate Screening Camp at – Nellore Dist.



Cleft Lip & Palate Screening Camp at – Nellore Dist.



Cleft Lip & Palate Screening Camp at - Gobichettipalayam



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