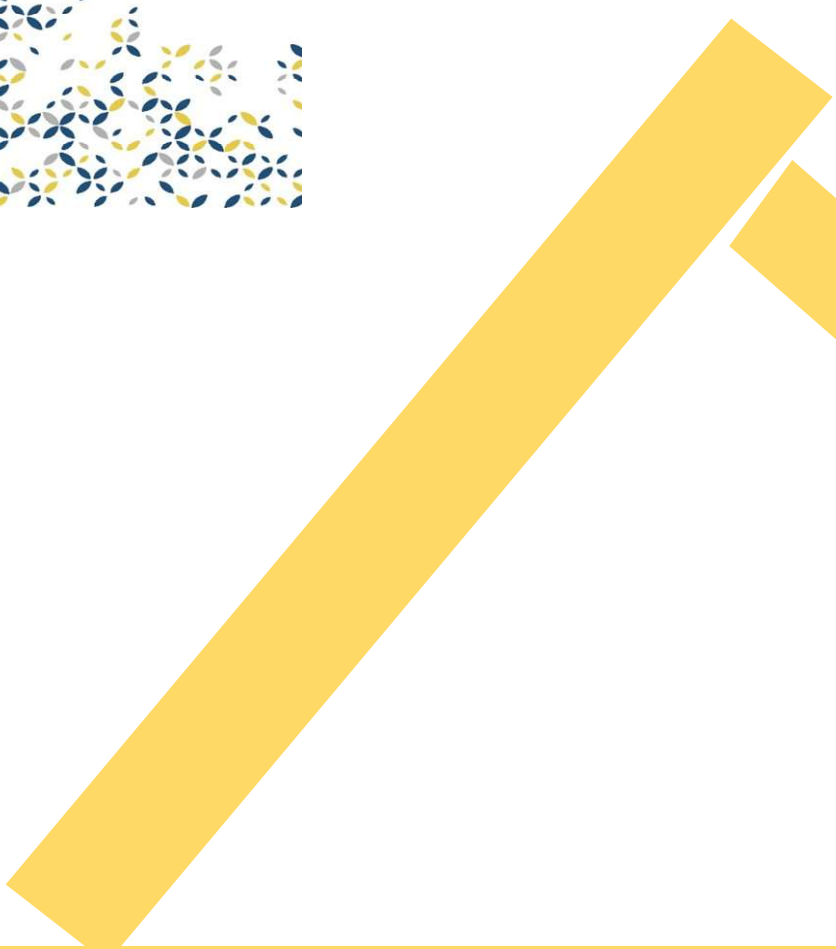
Persistent Foundation's Facial Cleft Project:

THIRD-PARTY IMPACT ASSESSMENT 2023-2024



Study conducted by Chhaaya-June 2025

Chhaaya
GROW AS YOU GIVE GIVE AS YOU GROW

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EXCEUTIVE SUMMARY

The evaluation focused on three ongoing and newly opened centers—Pune, Hyderabad, and Kolkata—selected for their scale, accessibility, and strategic importance.

- Data collection combined: Secondary data review (program records across 12 centers)
- Primary data collection (site visits and interviews with over 100 patient families and key surgeons)
- Stakeholder consultations (ABMSS leadership, program coordinators, partners)

Despite monsoon disruptions affecting some interviews, a representative sample was secured. Insights were further enriched through case studies from Annexures and assessed using an impact framework.

Key Findings

Program Reach and Relevance:

- Over 1,020 patients were treated in FY 2023–24 across 12 active centers.
- Expansion into urban hubs like Delhi, Kolkata, and Indore enabled improved access to comprehensive care.
- The program addresses a highly relevant, neglected healthcare need—free, accessible cleft care for economically disadvantaged families.

Quality of Clinical Care:

- High surgical volumes and skilled leadership across centers
- Comprehensive care: orthodontics, speech therapy, and nutritional counseling.
- Standardized protocols and custom-built apps improve surgical accountability.

Holistic Impact on Beneficiaries:

- Families report major improvements in children's appearance, feeding, speech, and school readiness.

- Program has reduced social stigma, improved emotional well-being and confidence.

Program Strengths:

- Strong clinical commitment and ethical governance.
- Effective government integration and community outreach.
- Financial inclusivity and comprehensive support (travel, stay, nutrition).

Challenges and Gaps:

- Gaps in speech therapy and follow-up care.
- Logistical challenges for rural families.
- Specialist shortages and limited co-funding options.

Strategic Recommendations

- Adopt a Project Mode Framework: Include admin and coordination costs for sustainability.
- Leverage Technology: Multilingual speech therapy videos and follow-up support via mobile.
- Mandate Comprehensive Care: Ensure all centers offer integrated services.
- Enable Co-Funding: Allow CSR/NGO partnerships to fill service gaps.
- Continue Ethical Expansion: Maintain real-time monitoring and strong governance.

Conclusion

The Facial Cleft Program demonstrates clinical excellence, institutional support, and transformative impact. It has helped thousands of children live healthier, more confident lives. Continued emphasis on holistic care, better support services, and funding flexibility will ensure even greater equity and reach in pediatric cleft care in India.

Persistent Foundation's Facial Cleft Project:

INTRODUCTION

Over the years, Persistent Systems Ltd. (PSL) has championed the 'Facial Cleft Surgeries and Comprehensive Care' program as its flagship Corporate Social Responsibility (CSR) initiative. This program has consistently received the highest level of funding within PSL's CSR portfolio, reflecting the company's unwavering commitment to making a meaningful impact in the lives of individuals affected by facial cleft conditions.

Originally launched in the financial year 2016-17, the program has steadily expanded its scope and reach each year. What began as a partial financial support initiative for surgeries has since evolved into a comprehensive healthcare program, addressing all facets of facial cleft-related care. Today, it encompasses surgical interventions, pre- and post-operative medical support, rehabilitation, and awareness initiatives to ensure holistic well-being for affected individuals and their families.

In recent years, the budget allocation for this program has increased significantly, reinforcing PSL's dedication to broadening its impact. In accordance with the CSR provisions outlined in the Companies Act 2013, this substantial investment necessitated a third-party assessment to evaluate its effectiveness and ensure accountability. To fulfill this requirement, PSL engaged Chhaaya Strategic Advisors LLP (Chhaaya) to conduct an independent impact assessment for the financial year 2023-24.

This report presents the findings of Chhaaya's assessment, offering insights into the program's outcomes, effectiveness, and the tangible difference it has made in the lives of beneficiaries. The evaluation serves as a crucial step in further strengthening PSL's commitment to delivering sustainable and high-impact healthcare support through its CSR initiatives.

SCOPE

Over the years, Persistent Foundation has been gradually expanding its Cleft Program outreach in partnership with Akhila Bharatiya Mahila Seva Samaj (ABMSS). As part of this initiative, several new treatment centers have been established to enhance accessibility and ensure comprehensive healthcare services for affected children.

Centres	Locations
Ongoing Centres	1. Bangalore 2. Hyderabad 3. Nagpur 4. Pune 5. Aurangabad 6. Pandharpur
New Centres	7. Kolkata 8. Delhi NCR 9. Sangli 10. Indore 11. Faridabad 12. Jaipur

The scope of the evaluation was to consider entire secondary data for analysis and qualitative primary data collected through personal visits to three centres – two ongoing and one newly opened centre. Furthermore, primary data was also collected through video conferences with other centres. This is explained in more details in the methodology section.

METHODOLOGY

To evaluate the impact of this expansion, a detailed analysis of secondary data was planned, covering treatment outcomes, and program performance across all centers. In addition, primary data collection was conducted through site visits to three key locations: Hyderabad, Kolkata, and Pune.

Hyderabad was selected due to its large-scale operations and its status as one of the earliest centers established under the program. Pune, being home to Persistent's headquarters, was chosen for its accessibility and the opportunity for direct stakeholder engagement. Kolkata was identified as the location with the highest number of cases covered among the newly established centers in the financial year 2023-24, providing valuable insights into patient reach and treatment effectiveness.

Method	Tools	Stakeholder Respondents
Video conferencing	Semi Structured Questionnaire	1. Dr Sagar Jangam, Pandharpur Nelson Mother and Child Care Hospital 2. Dr Ujwala Dahiphale, Aurangabad - Dahiphale Hospital 3. Dr. B.S. Jayanth, Bangalore -Rangadore Memorial Hospital 4. Dr Dushyant Prasad, ABMSS Bangalore
Personal Interviews	Semi Structured Questionnaire	1. Dr Vijay Kumar Hyderabad - AVR Dentofacial Hospital 2. Dr Sagar Jangam, Pune Birla Memorial Hospital, Pune 3. Ms Yogita Apte, Rushikesh Barsavade (Pune) and Ms Revika (Hyderabad)

A structured approach was adopted for both secondary and primary data collection:

- **Secondary Data Analysis:** Reviewing existing records, and past program performance data to assess trends and progress.
- **Primary Data Collection** – Summarization and Analysis: Engaging directly with stakeholders through:
  - **Site Visits:** Hyderabad, Kolkata, and Pune selected for on-ground assessments of healthcare infrastructure and service delivery effectiveness.
  - **Interviews & Surveys:** Gathering insights from patients, families, healthcare professionals, and administrators to evaluate satisfaction levels and operational challenges.

This evaluation will provide essential insights into the success of the Persistent Foundation's efforts in improving cleft care services and guide further advancements in the program's implementation.

Evaluation Deliverables

- A comprehensive report presenting findings, impact analysis, and data-driven insights.
- Recommendations for enhancing service delivery and optimizing future expansion plans.
- Strategic inputs to strengthen the sustainability and effectiveness of the initiative.

Sampling Limitations

The evaluation aimed to cover 10% of the total treated cases in the financial year 2023-24, which amounts to approximately 102 patients out of the 1,020 cases. This sample was to be assessed through direct interviews with patient families at the visited centers, as well as those participating via video conferencing from other locations.

However, the assessment faced logistical challenges due to persistent heavy rains across India during the scheduled visits and virtual consultations. As a result, some patients

traveling from distant areas were unable to reach the treatment centers, leading to unavoidable limitations in the coverage of interviews. Despite these challenges, every effort was made to gather comprehensive insights from the available patient families to ensure a meaningful evaluation of the program's impact.

Assessment Method and Scoring

- **Framework:**

Chhaaya has developed 6-point framework – Relevance, Adequacy, Effectiveness, Efficiency and Sustainability, and Persistent Mandate.

Parameters	Evaluation Questions
1. Relevance	How relevant are the issues being addressed by the project for the context and priorities of the stakeholders, including the concerned community?
2. Adequacy	Is the project interventions' coverage sufficient to address the issues and needs of community? Is the beneficiary size significant? Compared to the potential beneficiaries? In both absolute terms, as well as relative to the total coverage of PF?
3. Effectiveness	To what extend has the project achieved stated /committed objectives? Does the project address root causes of the issues being addressed, and has it transformed the baseline situation in satisfactory manner? What short term and long-term changes did the project have on the concerned community? Do they feel empowered by the outcomes?
4. Efficiency	Has the project achieved objectives / targets within timeline and budget? Did the project use resources diligently and

Parameters	Evaluation Questions
	achieve the outcomes in the most economical manner? Is there scope for further cost efficiency?
5. Sustainability	To what extent is the community involved in project? Is there sufficient ownership and contribution towards the project? What are the chances of continuation of the project and sustainability of the outcomes beyond Persistent' s support? Which stakeholders will take forward the project legacy?
6. Persistent Mandate	Does the project get brand visibility for Persistent? Is there scope for employee volunteering/donation? Does project get recognition externally or internally? Are there collaborations to extend project gains? How neglected is the issue which is selected for the project implementation?

Scoring: The evaluation questions were presented to various stakeholders, and their responses were collected. Based on the feedback received, a scoring system was applied. If the project met a specific criterion, it was awarded a score of 1; if it did not, a score of 0 was assigned. In cases where the criterion was only partially fulfilled, a score of 0.5 was considered.

The following tables list 30 different aspects organized in 6 different parameters; hence total score is against 30.

Parameters	If Y score 1, if N score 0, and for partially fulfilled condition score 0.5				
Relevance of the issue being addressed	Whether needy community targeted	Whether mandated by CSR Law	Whether issue relevant for implementing partners	Whether priority for development sector	Whether offsetting business footprint
Adequacy	Whether adequate outreach to demonstrate impact	Whether affected population covered adequately	Whether key stakeholders included	Whether different aspects of the issue covered	Whether different types of supporting interventions included
Efficiency (resource use / design)	Whether design included cost consciousness	Whether external resources mobilized	Whether costs were percolated to beneficiaries	% of overheads kept low	Whether similar outreach in similar budget projects
Effectiveness in changing situation	Whether beneficiaries satisfied	Whether defined objectives achieved	How was impact compared to similar projects	Whether problem symptoms removed	Whether root cause addressed
Sustainability of project processes and outcomes	Whether reflected in robustness of the design	Whether prospects of continuity beyond the project period	Whether impacts sustainable beyond project period	Whether adaptation (of intervention, process) likely	Whether processes institutionalized
Persistent Mandate	Visibility through Display boards, credit sharing,	Employee Engagement	Recognition: Internal recognition,	Collaboration: Institutionalized collaboration	Unique, best practices; Extremely

Parameters	If Y score 1, if N score 0, and for partially fulfilled condition score 0.5				
	acknowledgement by beneficiaries, references in formal documents	donations or volunteering	Awards, media clipping, case study: written documentation	with defined roles	critical and neglected issue addressed

Each condition is exclusive; they are not sequential.

Since the methodology combined both qualitative and quantitative assessment, the Chhaaya team had to exercise caution when determining scores. Their insights and experience played a crucial role in shaping the evaluation process.

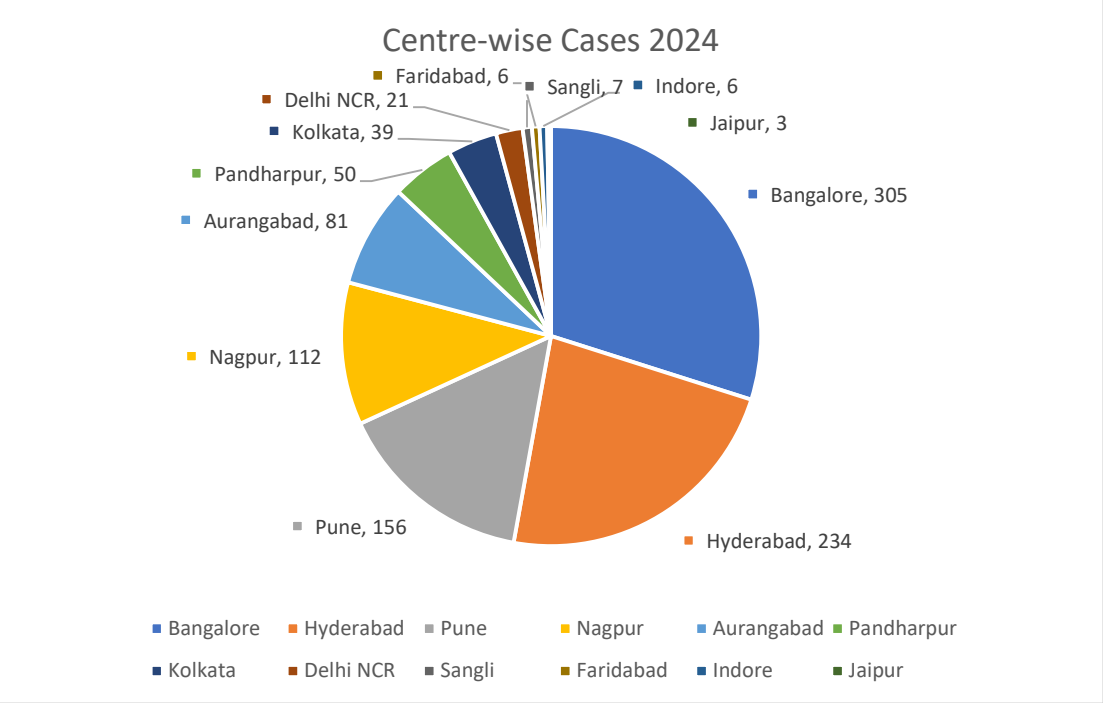
To truly capture the essence of the program's impact, a conscious effort was made to conduct personal interviews with as many patients as possible. These firsthand accounts provided invaluable insights into their experiences, perceptions of the quality of treatment delivery, and the effectiveness of surgical procedures in enabling their children to lead a normal life.

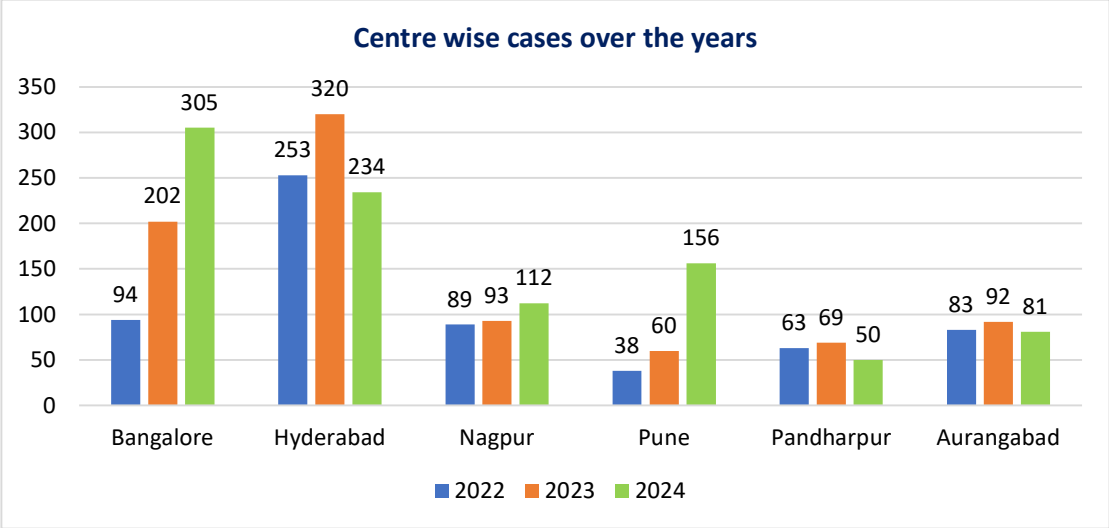
Beyond the medical aspect, the interviews also highlighted the financial relief offered by the program, as many families faced significant burdens due to the long and extended nature of cleft treatment. The program's support in easing these challenges was a crucial factor in improving overall well-being.

To ensure a comprehensive understanding of the impact, several patient stories have been compiled and attached as annexures to this report. These narratives serve as powerful testimonials to the transformative effect of the initiative. Additionally, the impact assessment includes a summary of key insights gathered from these interviews, offering a holistic view of the program's reach and effectiveness.

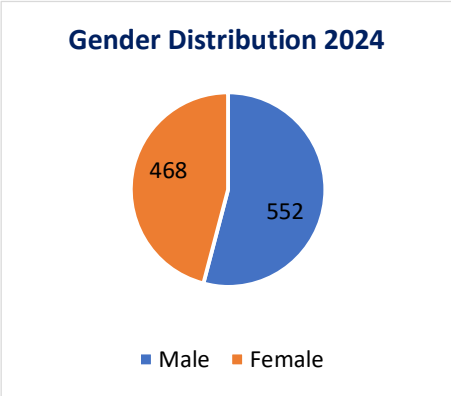
SECCONDARY DATA & ANALYSIS

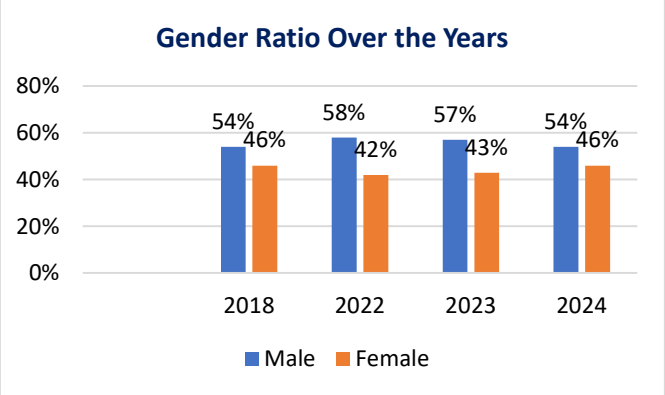
Outreach:



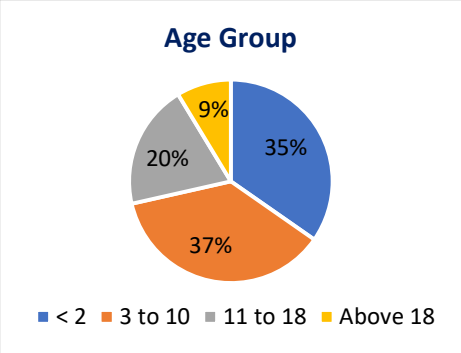


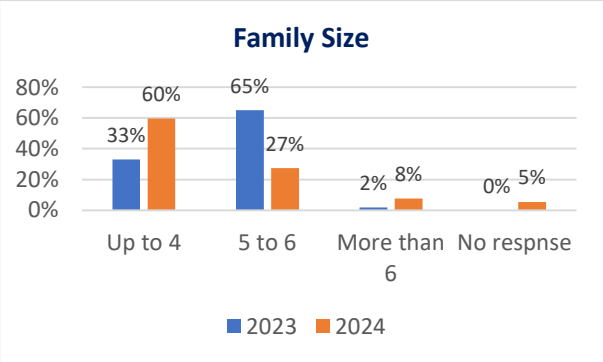
Gender Aspect

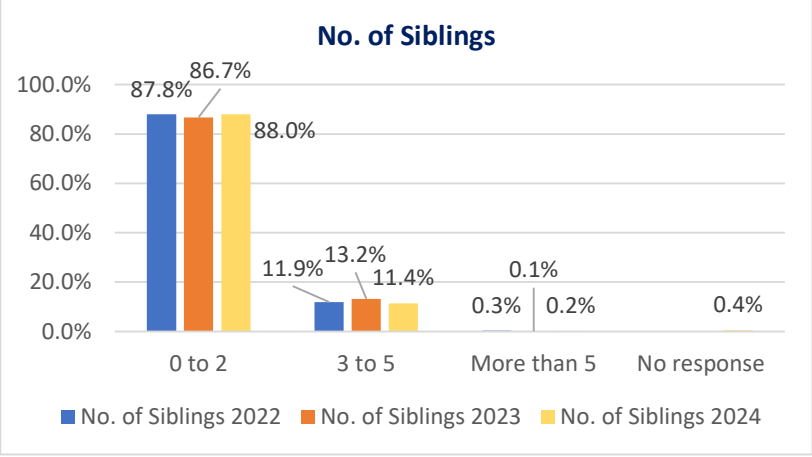




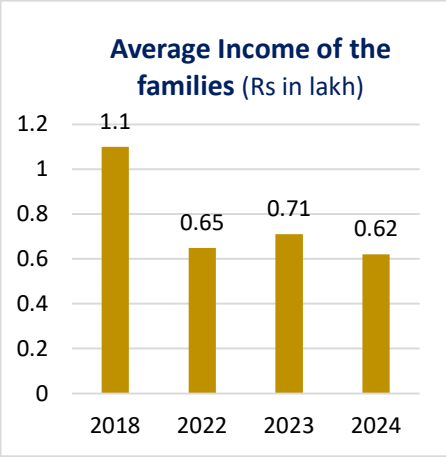
Age group of the patients, siblings and family size:

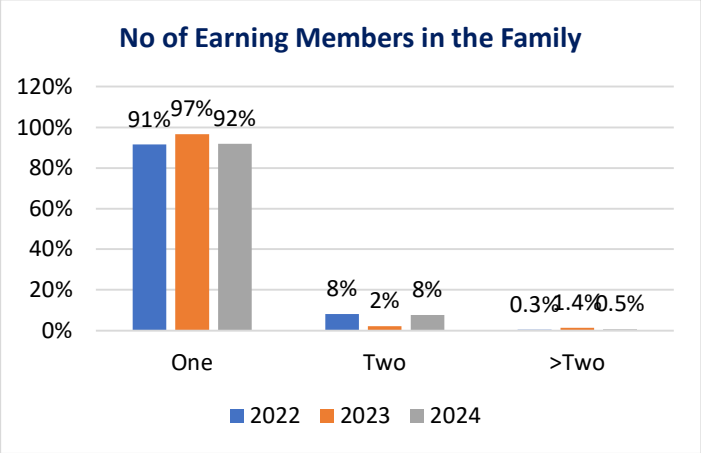






Average Income and Earning Members:





Rising Numbers, Growing Impact

How outreach and government partnerships are driving an increase in cleft treatments.

Over the years, the number of treated cases has grown significantly. This increase is primarily due to greater awareness, word-of-mouth referrals, and partnerships with government programs such as Rashtriya Bal Suraksha Karyakram (RBSK) and district hospitals. These initiatives have helped identify and treat patients earlier, ensuring better access to cleft-related surgeries and care. Certain centers, such as Bengaluru, Nagpur, and Pune, have seen a steady rise in cases compared to others.

Pune's Success Story: A Model for Comprehensive Care

Pune is leading the charge, with soaring patient numbers.

Pune has experienced more than a twofold increase, which can be attributed to its recognition as a center offering comprehensive treatment. Additionally, regular outreach camps have played a crucial role in spreading awareness, bringing more patients in—not because there is a surge in cleft disorder incidence, but because more families now seek treatment at established centers.

Aurangabad: Holding Steady in a Changing Landscape

Consistent caseloads amidst evolving treatment trends.

Unlike other locations experiencing rapid increases, Aurangabad has maintained a relatively consistent caseload, with fluctuations of fewer than 10 cases. This indicates that while new patients continue to seek treatment, the center has reached a stable operational level compared to the rapidly growing centers.

Beyond Surgery: The Need for Holistic Cleft Care

Why orthodontics, dental care, and speech therapy matter just as much as surgery.

Comprehensive care, including orthodontic treatment, dental care, and speech therapy, is available at most centers. However, newer centers in Indore, Faridabad, Delhi NCR, Jaipur, and Sangli have yet to fully integrate these services, which may lead to gaps in post-surgical care. The availability of these additional services is crucial, as cleft patients often require long-term follow-up treatments beyond surgery.

Kolkata's New Hope: A One-Stop Cleft Care Solution

How a hospital partnership is making treatment more seamless for patients.

Kolkata is one of the newest additions to the network, and ABMSS has successfully partnered with a well-equipped hospital, enabling all aspects of cleft care to be provided within the same premises. This is a major advantage, as patients do not have to seek different treatments in separate locations, making the process more seamless and effective.

A Pattern in the Data: More Boys Affected by Cleft Conditions

Exploring the persistent gender disparity in cleft cases.

Over the years, the data consistently shows that cleft conditions occur more frequently in male children than female children. This trend has remained steady, suggesting a

biological or genetic predisposition that influences the condition's occurrence. Understanding these trends helps researchers and healthcare providers tailor treatment strategies accordingly.

The Treatment Journey: A Step-by-Step Process

Understanding why cleft surgeries happen in different stages until age 15.

Among patients who undergo cleft surgeries, 35% are younger than 2 years, while 37% are between 3 and 10 years old. Many of these children have already undergone their initial lip and palate surgeries and are now proceeding to the next phase of treatment. Since cleft repair is a prolonged process that continues until around 15 years of age, multiple procedures are required at different developmental stages, ensuring proper speech development and facial growth.

Detect Early, Treat Better

How outreach programs are making a difference through early intervention.

One of the most significant benefits of outreach programs and government hospital collaborations is the ability to detect cleft conditions early and initiate treatment promptly. This helps prevent complications such as speech delays and feeding difficulties, improving the overall success of cleft management.

Shrinking Families, Changing Trends

What the rise in smaller families means for cleft patients.

Data suggests that families with up to four children are increasing, indicating a gradual decline in overall family size. This demographic shift may be influenced by factors such as family planning awareness, economic conditions, and healthcare access, which affect reproductive choices.

Stable Yet Evolving: Sibling Data Insights

Why household dynamics remain steady despite shifting family sizes.

Despite shrinking family sizes, the number of siblings per household has remained relatively stable over the past three project reporting periods. This suggests that while parents are having fewer children overall, the composition of households remains consistent, with similar sibling dynamics.

Financial Barriers and the Lifeline of Free Treatment

How income constraints make free surgeries essential for thousands.

Data shows that the majority of project beneficiaries come from families earning less than ₹1 lakh annually, with only one earning member supporting the household. This highlights the critical need for free or subsidized treatment programs, as these families would otherwise struggle to afford cleft-related surgeries and follow-up care.

PRIMARY DATA : OBSERVATIONS & ANALYSIS

Program Administration - Interactions with Dr Dushyant-ABMSS:

(Detailed interview is attached as Annexure-1 of this report)

Over the years, ABMSS has transitioned from a reactive, organically growing organization to a strategically expanding cleft care provider. Initially driven by incoming cases without active outreach, its turning point came around 2019, when structured expansion efforts and guidance from partners like Deutsche Cleft and Persistent Foundation led to targeted regional initiatives. Post-COVID, the focus shifted from rapid growth to consolidation and excellence, marked by the "Story of Change 2.0" framework. This phase emphasized creating comprehensive care centers offering integrated services such as speech therapy, dental care, and nutritional support, alongside innovations like US-based nasal stents and digital health records. With

surgical protocols standardized up to 96%, ABMSS also prioritized primary surgeries in underserved regions and centralized operations to improve efficiency and impact.

In recent years, ethical governance, technological integration, and financial sustainability have become key pillars. Hospital partnerships are now based on prior trust and proven transparency, with unethical centres being decisively shut down. The rollout of a custom-built app has enabled real-time surgical monitoring, geotagged documentation, and coordinated follow-ups, ensuring consistency and accountability. Strategically, ABMSS has concentrated services in metro cities like Delhi, Mumbai, and Kolkata—driven by donor preferences, patient demand, and healthcare infrastructure—while consolidating or reducing presence in smaller towns. Through tailored financial screening and consent protocols, the organization ensures support reaches genuinely needy patients. With a growing network of trusted hospitals and CSR partners, ABMSS continues to balance access, ethical practice, and sustainability, while expanding impact across India.

The Summary of the Interactions with the Surgeons:

Dr Sagar Jangam, Dr Jayanth, Dr Ujwala Dahiphale, Dr Siddharth Chatterjee and Dr Dushyant were interviewed to get their perspectives on the program. The detailed interviews are attached as Annexure-1 to this report. Main points emerging from their interview are mentioned below.

Across multiple ABMSS-supported centers, leading surgeons are dedicated to providing comprehensive cleft treatment despite financial and logistical challenges. Dr. Siddharth Chatterjee has been instrumental in cleft care since 2017, initially at Jain Trust Hospital before transitioning operations to Narayana Health in Bangalore in 2020. His Kolkata center expanded services to include orthodontics and speech therapy, though patient retention remains a challenge due to long travel distances. His outreach efforts, particularly in Bihar, have strengthened early intervention, and he has performed over 2,000 surgeries.

In Pune and Pandharpur, Dr. Sagar Jangam has played a vital role in cleft treatment for over five years, consolidating essential care in a single location. He actively supports expectant mothers through prenatal counseling, ensuring early preparedness for cleft-related challenges. However, submucous cleft palate, a complex condition, often remains undiagnosed due to limitations in prenatal screening, delaying treatment until speech impairments appear.

The Hyderabad Centre, under Dr. Vijay Kumar, treats around 200 cases annually, with isolated cleft palate cases becoming more prevalent. A concerning trend is that 20% of these patients also present with cardiac issues, requiring further study. Speech therapy faces challenges due to travel constraints and difficulties in implementing online therapy, especially in households with limited digital access.

At Bengaluru Centre, Dr. Jayanth oversees operations in partnership with Persistent and ABMSS. While funding remains strong, logistical hurdles complicate patient identification and follow-ups. Many families struggle with the financial strain of long-distance travel, while hospital capacity issues further impact service delivery. Speech therapy faces setbacks due to language mismatches between therapists and patients, compounded by budget limitations restricting hiring of experienced local therapists.

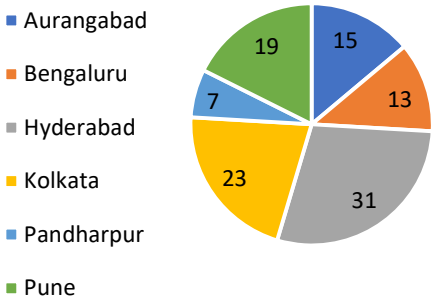
In Aurangabad, Dr. Ujwala Dahiphale continues to face high patient demand, driven by genetic and maternal health factors. However, financial limitations restrict treatments like fistula repair, while government hospitals prioritize trauma cases, delaying elective cleft surgeries. The center also lacks supportive services like speech and dental therapy, making external care unaffordable for many families. A reduced surgery quota in 2025–26 further affects patient access. Despite these barriers, the hospital remains committed to providing free cleft treatment, ensuring financial relief for affected families.

While these centers navigate operational constraints, their commitment to expanding cleft treatment remains unwavering. Targeted outreach, better funding models, and improved accessibility measures will be key to sustaining long-term impact.

The Summary of the Patient Families' Interviews:

(Detailed individual and group interviews are attached to this report as Annexure-3.)

Patients / Patient Families Interviewed



Summary: Cross-Regional Insights on Cleft Care in India

1. Socioeconomic and Geographic Background

- Families are predominantly from rural, semi-urban areas with low to middle-income.
- Fathers work as daily laborers, farmers, drivers, bidi workers, or vendors; mothers often cease working due to caregiving demands or cultural norms.
- Access to specialized healthcare is limited; free surgeries are often the only viable option.

2. Educational Status and Health Awareness

- Parental education is low, especially among mothers (often up to 5th–8th grade).
- Limited understanding of prenatal diagnostics and long-term cleft treatment needs.
- Better-educated mothers (especially in Bangalore) often take more active roles in speech therapy and follow-up care.

3. Prenatal Diagnosis and Decision-Making

- Clefts are frequently detected during the 2nd or 3rd trimester.
- Initial parental reactions include shock, fear, and stigma.
- Doctors' reassurance about surgical correction and spiritual beliefs often influence the decision to continue pregnancies.

4. Cultural Beliefs, Family Pressure, and Marriage Practices

- Cultural pressure surrounds birth of daughters, visible deformities, and expectations of motherhood.
- Consanguineous marriages are common and linked to increased cleft cases; some families now question the practice.
- Superstitions persist but are increasingly overridden by medical understanding and social referrals.

5. Feeding Challenges and Early Care

- Infants with cleft palate face milk leakage, undernutrition, and slow weight gain.
- Hospitals provide feeding clips, and some infants require ICU care due to related complications.
- Feeding issues often delay surgery, especially for palate repair.

6. Information Access and Referral Networks

- Families mainly learn about cleft care via Anganwadi workers, relatives, neighbours, religious leaders, YouTube, or local media.
- Word-of-mouth trust in specific doctors and hospitals (e.g., Nelson Hospital, Dahiphale Hospital) plays a critical role.

7. Financial Constraints and Relief

- Private surgeries are unaffordable, leading to immense emotional and economic distress.
- Discovery of free services (ABMSS, RBSK, Persistent Foundation) brings huge relief; in some cases, prevents emotional breakdowns or suicidal ideation.

8. Surgical and Long-Term Care

- Multiple surgeries are needed: lip repair, palate closure, bone grafts, and sometimes orthodontics and ENT care.

- Many families are unaware of the long-term nature of treatment at first.
- Follow-up therapies like speech and dental care are critical but often face logistical barriers.

9. Speech Development and School Integration

- Surgery significantly improves speech, appearance, and confidence.
- Mothers frequently lead home-based speech therapy, though access to professional services varies.
- Children become more socially accepted and ready for schooling, although some face delays.

10. Educational Aspirations

- Families prioritize education post-treatment, with children—especially girls—continuing school and aspiring to careers (e.g., teachers, officers).
- Some parents become advocates, helping others access similar care.

11. Social Stigma and Gender Dynamics

- Mothers often face blame or isolation within communities.
- Girls with cleft conditions face more stigma, yet families remain committed to their education.
- Successful treatment reduces stigma and strengthens parental resolve.

12. Emotional Resilience and Community Support

- Faith, family, and hospital counsellors help families cope emotionally.
- Despite challenges, families demonstrate remarkable resilience and gratitude for care received.
- Experiences prompt shifts in beliefs, especially regarding genetics, marriage practices, and the role of healthcare.

PARTNERSHIP AND PROGRAM ANALYSIS:

Consolidated Analysis of Persistent-ABMSS Cleft Program

(Based on Partner Interviews)

Overview

The ABMSS Cleft Program operates through a network of highly committed surgeons and partner hospitals across India, including in Kolkata, Pune, Aurangabad, Nagpur, Hyderabad, and Bengaluru (and other newer centres). Each centre brings unique strengths and faces distinct operational challenges, yet they are all unified in their mission to deliver comprehensive, equitable, and high-quality cleft care to underserved populations.

Key Strengths of the Program

Dedicated Clinical Leadership

Across all centres, surgeons like Dr. Siddharth Chatterjee, Dr. Sagar Jangam, Dr. Ujwala Dahiphale, Dr. Vijay Kumar, and Dr. Jayanth have demonstrated exceptional commitment, often going beyond their clinical roles to provide counselling, community outreach, and follow-up support.

Comprehensive Care Models

Many centres have successfully transitioned from basic surgical interventions to integrated cleft care, offering:

- Lip and palate repair
- Dental treatment
- Speech therapy
- Orthodontics
- Psychological and nutritional counselling
- Prenatal guidance (e.g., Pune centre)

Community Outreach & Awareness

Robust community engagement through regular camps, school programs, and referrals from RBSK has significantly improved patient identification and inflow, particularly in Kolkata, Pune, and Bengaluru.

High Surgical Volume and Expertise

With thousands of surgeries completed collectively, the program demonstrates high surgical competency, even in complex cases. For instance, Dr. Jayanth handles nearly 400 surgeries annually, and complex reconstructions like the Samiksha Kale case (Pune) highlight the program's advanced capabilities.

Common Challenges Across Centres

Gaps in Comprehensive Care Delivery

- Speech therapy remains a major unmet need due to shortage of trained local therapists, dialect mismatches, poor access in remote or low-income households
- Dental care is inconsistently available-particularly in Aurangabad, often requiring external referrals or informal support from dental professionals.

Logistical and Socioeconomic Barriers

- Many families travel 200–300 km for care, leading to dropouts after initial surgery.
- Patients from daily-wage or low-literacy backgrounds struggle with appointment scheduling, transportation and long-term follow-ups
- Government hospital referrals (e.g., for fistulas or submucous palate) are often delayed due to elective status and trauma case precedence.

Financial Constraints & Program Limitations

- Centres must work within surgery caps (e.g., Dr. Dahiphale's reduction from 84 to 40 surgeries/year).
- Funding exclusivity clauses prevent centres from collaborating with other organizations like Smile Train to fill critical service gaps.
- Online therapy or digital solutions are hindered by lack of smartphone access, especially in rural households.

Clinical Complexities

- Cases involving infants or co-morbidities (e.g., heart conditions) are riskier and require advanced facilities.
- Submucous cleft palate and late-diagnosed isolated palates (common in Hyderabad and Pune) often remain untreated until school age.

Demographic Observations

- Higher cleft prevalence in some regions, possibly due to consanguinity and regional health disparities.
- Patients in Kolkata often have better haemoglobin levels than those in other areas, enabling faster surgery.
- Certain religious and cultural communities, such as some Muslim populations and some Hindu castes, show higher cleft incidence—requiring culturally sensitive outreach.

BEST PRACTICES:

Best practices extracted from ABMSS's strategic evolution and operational refinement:

1. Strategic Expansion & Consolidation

- **Shift from Reactive to Strategic Growth**: Initially opportunistic, ABMSS transitioned to a structured, data- and need-driven expansion model targeting

underserved regions.

- **Focus on Consolidation Post-COVID**: Reoriented towards strengthening existing centres and enhancing quality rather than unchecked expansion.

2. Comprehensive & Holistic Care Model

- **Integrated Services**: Evolved from surgery-only to offering a full spectrum of cleft care—including speech therapy, dental, nutrition, and psychosocial support.
- **Centres of Excellence**: Established high-capacity urban centres with comprehensive services to serve as regional hubs.

3. Innovation & Cost-Effective Solutions

- **Technology Integration**: Use of specialized medical devices (e.g., nasal stents, bone grafting materials) to reduce complexity and cost of surgeries.
- **Custom App for Real-Time Monitoring**: A mobile app with geotagging, time-stamping, and live data feeds ensures surgical accountability and improves reporting efficiency.

4. Medical Standardization

- **Protocol Development**: Four-part standardization covering surgery, photography, documentation, and digital records ensures consistent, high-quality care across centres.
- **Instrument & Consumables Standardization**: Annual updates based on volume, enhancing both quality and cost-efficiency.

5. Ethical Governance

- **Strict Hospital Vetting**: Hospitals and surgeons must be independently known and vetted to prevent unethical practices.
- **Transparency Measures**: Photo consent forms, income verification, and multilingual documentation ensure informed and ethical patient engagement.

- **Whistleblower System**: WhatsApp helpline empowers patients and families to report misconduct anonymously.

6. Targeted Outreach & Primary Focus

- **Primary Surgery Priority**: Focused on unoperated cleft patients to maximize life-changing impact; secondary cases handled selectively.
- **CSR-Driven Location Planning**: Urban centre focus aligns with donor preferences and infrastructure advantages, optimizing patient inflow.

7. Financial Inclusivity with Accountability

- **Flexible Financial Screening**: Beyond BPL cards, holistic evaluations ensure support reaches genuinely needy families, with documented exceptions for borderline cases.
- **Balanced Private & Free Surgery Model**: Surgeons can offer private surgeries under regulated terms without compromising access to free care.

8. Operational Oversight

- **Regular Audits & Blind Checks**: Continuous hospital inspections and mystery audits maintain standards and correct deviations swiftly.
- **Expanded Oversight Team**: Dedicated medical supervisors and advisors ensure program integrity across locations.

9. Sustainable Management Practices

- **Shared Administrative Cost Model**: Apportioned salaries and fixed budget allocations for project management sustain operations.
- **Partnerships for Non-Surgical Needs**: Collaboration with suppliers for reduced-cost essential items strengthens long-term affordability.

CONCLUSION:

Cleft care in India is deeply shaped by economic status, cultural norms, family dynamics, and access to information. Across regions, families show resilience and commitment, but require sustained support, long-term care plans, and community-based awareness programs to ensure better outcomes.

Physical Impact:

Improved Appearance: Surgical correction significantly enhanced the children's facial features, boosting their self-esteem and social acceptance.

- Better Eating and Nutrition: Corrective surgeries eliminated feeding difficulties such as milk leaking through the nose and choking, enabling children to eat normally and sustain proper growth.
- Reduction in Infections: The palate surgeries reduced frequent infections of respiratory tract.
- Enhanced Speech: Post-surgery, children showed remarkable progress in speech development, moving from limited or no speech to clearer articulation and meaningful communication.
- Overall Health and Development: Improved feeding and speech contributed to better physical health, growth, and social functioning.

Emotional Impact:

- Restoration of Confidence and Dignity: Families, especially children, gained confidence through improved appearance and communication skills, fostering social integration.
- Reduced Social Stigma: Surgery helped diminish societal misconceptions, reducing feelings of shame or unacceptability that initially surrounded the children's conditions.
- Increased Social Participation: Children are now able to participate more actively in school and community activities, fostering friendships and social bonds.

- Parents' Emotional Relief: Families experienced immense relief and gratitude, alleviating stress associated with financial burden, societal judgment, and concern for their children's future.
- Hope and Optimism: The journey of treatment instilled hope for a better future, with parents envisioning social acceptance, education, and marriage prospects for their children.
- Overcoming Psychological Barriers: Families' trust in the treatment process helped break down scepticism and fears, leading to positive emotional transitions.

Impact of Free Surgical Interventions:

- All families benefited from free cleft surgeries, which were financially unaffordable otherwise.
- Support included not only surgeries but also travel, food, and accommodation assistance.

Delayed and Missed Support Services:

- Many children missed early therapies like speech therapy due to family health issues, lack of awareness, or logistical challenges.
- Over time, the benefits of surgical correction became evident, improving speech, appearance, and eating.

Lack of Prenatal and Early Support:

- Though most families were aware of the condition prior to birth prenatal counselling was not available to most of them.
- For the families who were not aware of the condition, absence of prenatal diagnosis and prenatal care led to initial shock and societal stigma.

Community and Family Support:

- Despite societal misconceptions, families showed resilience and support for affected children.
- Outreach and awareness campaigns played a critical role in linking families to treatment.

Challenges in Access and Logistics:

- Long travel times (~2-4 hours) to treatment centres were common and stressful.
- Limited education levels and economic constraints increased the difficulty of accessing care.

Family Sacrifices and Emotional Journeys:

- Families faced significant emotional stress, economic sacrifices, and sacrifices such as selling land (when they did not know about free surgeries) or delaying other health treatments.
- All parents expressed gratitude for the opportunity to seek treatment.

Community Skepticism & Breaking Myths:

- Some families initially doubted free surgical benefits, suspecting hidden motives.
- Successful outcomes helped shift perceptions toward acceptance and trust in free treatment programs.

Hope and Future Prospects:

- Families are optimistic about their children's future education, social integration, and marriage prospects.
- Treatment is seen as life-changing, restoring dignity and confidence.

Role of Program Outreach and Support Structures:

- Field coordinators, outreach camps, and community networks are vital in identifying and guiding families.
- Support extended beyond medical care, including counseling, travel, and nutritional aid.

Expansion of Comprehensive Cleft Care

- Several new centres opened increasing the scope of cleft care surgeries and treatment in other areas of the nation.
- Every year there has been an increase in the total number of cases treated highlighting the need for such a program.
- Kolkata transitioned from short-term surgical camps to long-term multidisciplinary care including orthodontics, speech therapy, and follow-ups. Over 4,300 patients have been treated across two facilities since 2017.
- In Aurangabad despite high demand and dedication, care is limited to basic surgeries due to funding restrictions. Supportive services like dental and speech therapy are absent or externally sourced.
- Bengaluru is one of the busiest centers, performing ~400 surgeries annually. Strong referral network via RBSK and government schools, but logistical and bed-capacity challenges hinder expansion.
- Pune focuses on prenatal counselling and early detection, addressing cleft care holistically. Patient volume has increased by ~30%, aided by streamlined in-house services.

Common Challenges Identified

Funding Limitations:

- Restrict expansion of non-surgical care (speech, dental).
- Lower surgical quotas (Aurangabad's quota is reduced for 2025–26).

- ABMSS policy limits the ability to accept *external funding* for supplemental services.

Geographic & Logistical Barriers:

- Patients travel long distances (200–300 km), making follow-ups difficult.
- Daily wage laborers and elderly caregivers struggle with repeated visits.

Specialist Shortages:

- Language mismatch in speech therapy (e.g., non-local therapists in Karnataka).
- Inadequate access to trained paediatric anesthetists and dental professionals.

Approval & Administrative Delays:

- Fistula surgery approvals (Aurangabad) take time, leading to patient dropouts.
- Bed shortages (Bengaluru) delay surgeries despite demand.

Social, Cultural & Medical Insights

Higher Incidence Factors:

- Consanguineous marriages and certain regional demographics (e.g., Muslim communities in WB) show substantial cleft cases.
- Better haemoglobin levels in WB patients aid surgery readiness.
- High birth loads in government hospitals hinder early detection of submucous clefts.

Delayed Diagnoses:

- Submucous cleft palates often go undiagnosed until speech issues emerge (age 7–8).
- Prenatal scans rarely detect cleft palates due to technical constraints.

RECOMMENDATIONS

Need to implement the program in Project Mode:

Initially, Persistent supported only surgeries, without funding comprehensive care. In 2018–19, we had recommended a broader approach that included speech therapy, nutritional support, and other essential services. Today, almost all centres provide comprehensive cleft care except may be Aurangabad. However, beyond direct project expenses, managing a large-scale operation requires investment in team salaries, travel, and administrative costs. Understanding both corporate and NGO perspectives, we recognize the importance of balancing financial sustainability with impactful service delivery. While Persistent supports coordinators at treatment centres, office management expenses are not currently covered. Including these may enhance the project outreach and quality of delivery.

Addressing Speech Therapy Concerns:

Centres are struggling with speech therapy sessions. The families which travel long distances for the surgeries are unwilling to do so for frequent speech therapy sessions. Sometimes there are also language barriers to fully comprehend the essence of therapy. All these could be overcome by developing online sessions in different languages and uploading them on the YouTube. They can be made free to all and the patient care takers can use them as per their convenience. Follow up phone calls may keep up the motivation and pressure to keep the therapy going.

Comprehensive Care Model to be Uniform in every Centre:

It can be observed that comprehensive care models have better success. Hence, for upcoming centres, this model can be made mandatory. It also needs to be operational in Aurangabad Centre.

Funding Issues:

In centres where there is unmet requirement due to stressed funding, co-funding model can be designed – either with other corporates or NGOs.

Screening of Patients for Economic Status:

In a few instances, concerns arose regarding the beneficiaries' economic status. If such cases surface, a justification must be provided for selecting a patient who seemingly has the means to afford treatment. Factors such as having a single earning member or significant financial burdens on the family may explain the decision.

CONCLUSION

The impact stories from patient families collectively highlight that free, accessible cleft treatment dramatically transforms lives—not only medically but emotionally and socially. Despite initial challenges such as societal stigma, logistical hurdles, and economic hardship, families demonstrate resilience, gratitude, and hope. Effective outreach, community involvement, and comprehensive support systems are essential in ensuring children receive timely care, leading to positive, lifelong impacts.

The ABMSS Cleft Program is a testament to what can be achieved through clinical excellence, institutional support, and community trust. While core surgical services are consistently strong, the real opportunity lies in scaling holistic care, bridging gaps in follow-up support, and reducing drop-offs.

The ABMSS network of cleft care centres demonstrates strong surgical expertise and commitment to long-term patient care. However, systemic challenges—especially around funding, specialist availability, and logistical barriers—continue to limit the potential for comprehensive, uninterrupted care. Centres like Kolkata and Bengaluru are models of scale and outreach, while Aurangabad and others highlight the critical need for expanded support services and flexibility in funding mechanisms by expanding funding flexibility, leveraging technology, and strengthening local ecosystems for speech

and dental care, ABMSS can set a new national standard for comprehensive cleft care that is both accessible and equitable.

Initially, Chhaaya advocated for directing CSR funding toward projects that maximize collective benefit, ensuring that every rupee supports the greatest number of beneficiaries. The initial suggestion was to finance individual cases through employee volunteering. However, impact stories revealed that this project is truly life-changing for its recipients. Given the long-term, high-cost treatments that marginalized families could scarcely afford for their children, substantial corporate backing is essential. Recognizing this, Persistent has been expanding its reach across India to maximize outreach. Over time, the project has proven immensely rewarding, as it integrates patients into the mainstream—individuals who might otherwise have been left behind.

IMPACT ASSESSMENT FRAMEWORK:

Parameters	Relevance of the issue being addressed from the point of view of					Total
Aspects	Beneficiary Community	The CSR mandate	Implementing partners	Development sector	Business footprint	
	1	1	1	1	0	4
	Most relevant	Child health	Solely dedicated to the cause	Child health is a priority	No direct relation	
Parameters	Adequacy of Project outreach to demonstrate impact					
Aspects	Absolute outreach	Extent of coverage of affected populations	Inclusion of key stakeholders	Various aspects of the issue addressed	Variety of interventions	
	1	1	1	1	1	5
	Maximum possible outreach	Saturation approach	All imp stakeholders included	All aspects addressed	Comprehensive model	
Parameters	Efficiency in resource Use / project design					
Aspects	Cost Consciousness	Mobilization of external resources	Percolation to the beneficiaries	% Overhead costs	Outreach in similar budget projects	
	1	0.5	1	1	1	4.5
Parameters	Effectiveness in changing situations					
Aspects	Beneficiary satisfaction	Achieving defined Objectives	Impact compared to similar Projects	Removal of problems symptoms	Addresses root causes of the problems	
	1	1	1	1	0.5	4.5
Parameters	Sustainability of project processes and outcomes					
Aspects	Reflected in robustness of the design	Prospects of continuity beyond the project	Sustainability of impacts	Adaptation (of intervention, process)	Institutiona-lization	
	0.5	0.5	1	1	1	4
Parameters	PSL's mandate (impact, visibility, employee engagement)					
Aspects	Visibility of the organisation	Neglected issue	Employee volunteering	External Recognition	Collaboration (for scale up)	
	1	1	0.5	1	0.5	4
Total Score						26

ANNEXURE-1: ABMSS – CLEFT PROGRAM THROUGH THE YEARS

Interactions with Dr Dushyant, ABMSS

Over the past few years, our strategy has evolved significantly. When we first started, growth was largely organic, driven by incoming applications from hospitals and individuals rather than proactive outreach. For the first five years, we accepted projects as they came, without actively marketing our services. By 2019, we recognized the need for structured expansion and began targeted efforts to attract both surgeons and hospitals. Organizations like Persistent Foundation and Deutsche Cleft played a crucial role in guiding our expansion based on geographical needs, leading to initiatives such as the Anantpur project and similar efforts in Gujarat, supported by ABB.

Post-COVID, we reassessed our approach, shifting towards consolidation rather than rapid expansion. This led to the introduction of "Story of Change 2.0," marking a new phase for ABMSS. Previously, our efforts focused primarily on surgeries and awareness camps, with speech therapy added as an ancillary service. However, we sought to create fully integrated centres of excellence, ensuring comprehensive care beyond surgery. While Hyderabad and Bengaluru achieved this vision, Nagpur, Pune and Kolkata followed a stepped-down model, offering comprehensive services but with certain limitations.

Recognizing the importance of holistic care, we introduced innovative solutions to enhance patient treatment. These included specialized feeding bottles, nasal stents, nutritional support, and advanced bone grafting materials to reduce surgical complexity. Standardizing sutures and medical supplies became a priority to ensure consistency and cost efficiency. Additionally, we integrated high-tech devices from the US to facilitate nasal moulding, enabling surgeons to begin pre-surgical interventions without needing orthodontic specialists.

Standardizing medical practices became another focus area. We developed a strict protocol encompassing four aspects: surgical treatment, photography and documentation, digital record-keeping, and best practices. This framework ensures consistency across centres while maintaining high-quality care. To support this, we engaged senior medical advisors from both India and abroad, facilitating discussions and training sessions with surgeons. Today, we have achieved approximately 95–96% standardization in surgeries.

As the organization matured, managing an increasing number of centres became challenging. At its peak, we had over 43 centres, prompting us to consolidate operations for better efficiency. A key shift in focus involved prioritizing primary surgeries—fresh cases of unoperated cleft lips and palates—rather than excessive secondary procedures. While we continue providing secondary surgeries, we emphasize expanding outreach to reach as many new patients as possible. This approach led us to strategically open centres in regions with higher numbers of untreated cases.

In recent years, we have refined our strategy through focus group meetings, engaging key stakeholders—including surgeons, board members, and donors—to ensure alignment with ethical best practices. By restructuring our reach, identifying areas with a greater influx of new cases, and maintaining our commitment to comprehensive care, we aim to maximize our impact while ensuring sustainable growth.

In recent years, our approach to expanding cleft care services has evolved to ensure efficiency and sustainability. The new project in Delhi is strategically positioned to serve as a major referral hub, while in Mumbai, we have finalized agreements to open a new centre at SL Raheja Hospital, which is expected to receive a high volume of primary cases. Pune has also benefited from facilitation through the RBSK program, similar to Hyderabad, Bangalore, and Kolkata, all of which receive fresh cases through these networks.

Initially, our project selection was largely opportunistic, accepting cases as they came. However, as the organization grew, we recognized the need for a more structured approach. One key factor influencing location selection is CSR funding availability. While Persistent supports Maharashtra, many donors prefer projects in urban centres rather than remote locations. This realization led us to focus on establishing comprehensive care centres in major cities, such as Kolkata, Delhi, Mumbai, and Chennai, enhancing visibility while meeting patient needs.

Patients themselves also prefer treatment in larger cities, believing they offer better medical services. This shift impacted our centres in smaller locations like Coorg and Mysore, where operations have significantly reduced. As Bangalore expands, it has become the primary destination for cleft treatment in Karnataka. Similarly, Mumbai and Pune now serve Maharashtra, while Kolkata and Delhi have emerged as key hubs.

In Delhi, our journey began with a hospital in Faridabad, but ethical concerns regarding patient billing and improper financial practices led us to discontinue operations there.

Transparency and patient welfare are core to our mission, so when investigations revealed unethical practices—including charging patients despite receiving funding for free surgeries—we shut down the center. To further safeguard patient rights, we implemented a WhatsApp helpline across all hospitals, allowing families to report concerns. This system proved effective in Ahmedabad when a tea vendor informed a patient's family about available support. Upon verifying complaints about unauthorized charges, we swiftly closed the facility, ensuring ethical medical practices.

These experiences shaped our hospital selection criteria. Rather than accepting any hospital or surgeon seeking partnership, we now require both the hospital and the surgeon to be independently known to us before collaboration. This approach was applied in Pune with Aditya Birla Hospital, where we onboarded Dr. Sagar, a trusted surgeon previously working in Pandharpur. Similarly, in Kolkata, we shifted operations from Shri Jain Hospital to Narayana Health, ensuring corporate-level infrastructure and end-to-end comprehensive care. In Delhi, our new hospital selection is guided by the same principles.

Additionally, we focus on providing surgeons with opportunities for professional growth within corporate healthcare settings. For example, in Delhi, Dr. Ravikant Singh, our surgeon in Varanasi, was invited to operate in the city since he also resides there, optimizing his availability while ensuring consistent, high-quality cleft care.

Through these strategic decisions, we continue refining our expansion model, balancing patient accessibility, ethical medical practices, and long-term sustainability. Let me know if you need further refinements!

To expand operations in Delhi, we identified a trusted surgeon and collaborated with a hospital we had prior connections with. This ensured full oversight of the process, preventing any internal mismanagement. To maintain transparency, we developed an app over the course of a year, testing its functionality before implementing it across 50% of our centers. Locations such as Kolkata and Pune already utilize tablets that support the app.

The app enforces real-time documentation by requiring geotagged, time-stamped patient photos taken directly within the app. This prevents the misuse of old images. Additionally, surgeons must take a selfie with the patient during surgery, ensuring that only authorized professionals perform procedures. The app captures further details, such as surgical numbers, eliminating the need to wait until the end of the month for updates.

By mid-month, we have real-time data on surgeries across different locations, enhancing tracking and reporting accuracy.

Beyond surgical monitoring, the app streamlines coordination for follow-up procedures. If a patient requires additional surgery, the app automatically prompts the surgeon. It is accessible to surgeons, coordinators, orthodontists, and speech therapists, allowing seamless scheduling of future treatments. This contributes to maintaining standardized medical protocols, consumables, and surgical instruments across centers.

Standardizing instruments ensures quality care while optimizing costs. Based on patient volume, centers receive updated instruments annually or biennially. Persistent has also supported equipment procurement in recent years, further aiding our efforts. As we continue expanding, our priority remains reaching more patients, particularly children requiring primary cleft surgeries. While follow-up treatments like orthodontics are available, they require long-term commitment, and data from Kolkata indicates a dropout rate of nearly 30%. To maximize impact, we focus on providing primary surgeries while reserving follow-up care for dedicated patients.

Our evolving strategy centers on patient needs rather than organizational objectives. With approximately 4,700 surgeries performed annually, screening processes ensure that economically weaker sections receive support. Government referrals under RBSK strengthen accessibility in Karnataka, Telangana, and Maharashtra, helping us reach underserved communities. While financial eligibility is assessed beyond formal BPL criteria, priority is given to families genuinely requiring assistance.

Cleft treatment costs in private hospitals exceed ₹1,00,000, with additional expenses like nasal stents and bone grafting pushing costs to ₹2,00,000. By offering free surgeries, we relieve families of this financial burden, ensuring that children receive life-changing treatment regardless of their socioeconomic background.

Patients requiring cleft surgery are often asked to return for follow-up procedures after six months or a year. To make treatments more accessible and cost-effective, we secured nasal stents from the US at a significantly reduced price—about 15% of the original cost. Similarly, we partnered with a Swiss company to obtain bone grafting material at a lower cost after demonstrating the impact of our work. Initially, we purchased these materials, but when affordability became an issue, the company provided them at the lowest possible price, ensuring continued access to essential medical supplies.

To maintain ethical transparency, our organization has implemented strict documentation protocols. Patients must sign a photo consent form permitting ABMSS to use their images for marketing, donor updates, and research purposes. This form also includes an indemnification clause, ensuring that any surgical risks remain between the patient and the hospital. The consent form is available in both local languages and English, ensuring accessibility. Additional forms include the hospital consent form for surgery approval, the discharge summary, and the income declaration form, which patients submit to verify financial eligibility.

Screening for financial need is conducted by hospital teams, and patients must certify their income. While we primarily serve economically disadvantaged patients, exceptions are made based on individual circumstances. For example, a 25-year-old Tech Mahindra employee reached out for cleft surgery through our WhatsApp helpline. Although he earned ₹35,000–40,000 per month, he was supporting his family, and after reviewing his salary slips, we granted the free surgery. This case highlights the importance of evaluating financial hardship beyond surface-level income levels.

We recognize that appearances can be deceptive, and financial eligibility must consider broader responsibilities and challenges. For select cases, free surgery is provided even if patients do not meet strict financial thresholds, with justification recorded to ensure accountability. Additionally, hospitals have been empowered to address cases where patients can afford private surgeries. In Delhi, for instance, well-off patients sought free treatment, leading the hospital to request authorization for private surgeries. Our policy allows surgeons like Dr. Siddharth (who works full-time with ABMSS) to perform private surgeries on weekends, ensuring ethical separation between free and paid cases.

To maintain fairness, private surgeries are strictly monitored, ensuring that priority remains on free procedures. Hospital visits by our medical and program teams help oversee operations and uphold ethical standards. Institutions like Narayana, SL Raheja, and Aditya Birla uphold these values, ensuring high-quality care for both free and private patients without compromising accessibility.

Hospitals partnering with ABMSS provide cleft care services at the same high standards as those offered to their private patients. In Delhi, for example, a dedicated cleft ward has been established, ensuring specialized treatment for all patients. Aditya Birla Hospital has also set up a cleft ward, demonstrating a strong commitment to accessible healthcare. While private patients receive additional amenities like private rooms, the medical care itself remains consistently high across all patients.

To maintain quality and accountability, we conduct regular hospital visits. Each visit involves two representatives—one from the medical team and one from our office staff. Our medical oversight team includes Dr. OP Karnanda as a medical advisor, along with a medical director and three medical supervisors. Previously, only one person handled medical inspections, but with increasing operations, the team has expanded. These visits cover hospital wards, operation theaters, and patient interactions, ensuring adherence to ethical and medical standards. In addition to standard audits, blind investigations are occasionally conducted to identify and address any irregularities. While no system is entirely flawless, we ensure that any discrepancies are swiftly resolved.

As our organization grows, securing additional funding for operational costs has become a priority. New CSR partners have begun covering portions of administrative expenses, but further support is needed to ensure sustainable growth.

For certain CSR-supported projects, we allocate 8–10% of the total budget for fixed project management costs. Additionally, salaries for project managers and directors are apportioned across multiple initiatives to balance funding needs. As we continue discussions with Persistent and other partners, securing dedicated funding for management expenses would significantly strengthen program efficiency.

ANNEXURE-2: SURGEONS' PERSPECTIVES

Interactions with Surgeons:

Dr Siddharth Chatterjee-Kolkata Centre:

Since 2017, Dr. Siddharth Chatterjee has been an integral part of ABMSS, bringing his expertise in cleft surgery to the organization. After completing his medical training in 2015, he collaborated with ABMSS to establish a cleft care center at Jain Trust Hospital, which treated over 2,000 patients until its closure in 2020. Recognizing Kolkata's high prevalence of cleft cases, he expanded services beyond primary surgeries to include orthodontic care and speech therapy, focusing on long-term patient support rather than short-term surgical camps.

Despite the success of Jain Trust Hospital, operational challenges and the impact of COVID-19 led to its closure. To ensure continued care, ABMSS partnered with Narayana Health in Bangalore, where over 2,300 cleft patients have been treated. The center offers comprehensive cleft treatments, including dental care, palate repair, rhinoplasty, lip correction, and speech therapy, prioritizing patient care over administrative management.

While patients express satisfaction with treatment, follow-up care remains a challenge, particularly for those traveling long distances. To improve patient retention, motivational assessments, targeted outreach programs, and structured awareness initiatives are conducted. The center also engages in regular outreach efforts, strengthening relationships with communities in Kolkata and Bihar through scheduled visits and awareness camps.

West Bengal's high incidence of cleft conditions is influenced by genetic factors, consanguineous marriages, and demographic patterns, while government welfare programs contribute to improved early detection and intervention. Patient retention efforts focus on ensuring follow-ups every six months, particularly for orthodontic and

speech therapy cases. Surgical operations at the center have increased significantly, rising from 8–10 cases in 2022-23 to 39 in 2023-24, with further growth expected.

Most cleft surgeries involve infants aged 3–5 months, requiring specialized procedures. The partnership with Narayana Health has strengthened pediatric surgical infrastructure, providing advanced care for complex cases. Dr. Chatterjee, as the sole surgeon at the center, has successfully performed over 2,000 cleft surgeries, demonstrating his expertise and dedication to patient care.

The center operates independently under ABMSS, though Dr. Chatterjee initially trained at a SmileTrain facility before formally joining ABMSS. Securing funding remains crucial to sustaining high-quality treatment. Lower-budget hospitals often struggle with post-operative care, making the support of organizations like ABMSS and Persistent essential in ensuring comprehensive cleft treatment for all children, regardless of financial background.

Dr Sagar Jangam-Pune and Pandharpur Centres:

Dr. Jangam has been actively involved in the ABMSS program, particularly the Persistent-funded initiative, for over five years. Over time, he has witnessed a steady increase in the number of patients, largely due to extensive outreach efforts. Today, individuals travel from distant cities like Yavatmal for treatment.

Not only does the center provide high-quality care, but it also ensures a seamless experience for patients. All essential services are available in one location, eliminating the need for patients to move between buildings. While the number of cases has risen by nearly 30%, the types of conditions being treated remain consistent. However, there has been an increase in the number of isolated cleft palate cases.

A significant addition to the program is prenatal counseling**,** which helps expectant mothers prepare for their child's needs. When a cleft condition is detected via sonography, doctors now refer mothers to the center for guidance. Dr. Jangam plays a

crucial role in counseling these patients, particularly in feeding techniques, ensuring they are well-prepared.

Cleft lip is generally visible in sonography, but cleft palate is often missed. Unless the baby happens to open its mouth during the scan, the condition remains undetected. As a result, isolated cleft palates frequently go unnoticed. Even after birth, parents may fail to recognize the issue. Some children are only diagnosed at seven or eight years old, when speech difficulties become apparent. Without seeking medical advice, families may not realize their child has a cleft palate.

Another condition, submucous cleft palate, poses an additional challenge. In this type of cleft, the muscles in the soft palate fail to fuse properly during fetal development, but the mucous membrane remains intact, making it difficult to detect—even for doctors. Given the high volume of births in government hospitals, it is nearly impossible to thoroughly examine every child for such anomalies.

Dr. Jangam also shared the remarkable case of Samiksha Kale, who had a cleft extending to her eye. This rare condition left her unable to see with one eye. The surgery was highly complex, but Dr. Jangam successfully performed the procedure. Following her initial surgeries, she underwent bone grafting and is now receiving orthodontic treatment. She also had large polyps in her nose, which were surgically removed, allowing her to breathe through her nose for the first time at the age of 24.

Samiksha is overjoyed that her health concerns have been addressed, and her improved quality of life is a testament to the life-changing impact of comprehensive cleft care.

Dr Jayanth-Bengaluru Centre:

Dr. Jayanth's Bengaluru Centre maintains a strong partnership with Persistent and ABMSS, with no concerns about funding or operational support. However, the challenge lies in creating a sustainable ecosystem to fully maximize the program's potential and ensure long-term impact.

A key component of the centre's success is its referral system, which benefits from close collaboration with RBSK and government school programs. While these initiatives generate a significant number of patient referrals, logistical hurdles complicate patient identification and transportation for screening. A single program coordinator directs patients to district hospitals for haemoglobin testing, ensuring that individuals with low haemoglobin levels or respiratory infections postpone their travel—often 200–300 km—to RMH to avoid unnecessary trips and ensure they are medically fit for surgery. Beyond medical concerns, families face additional challenges, including difficulties in booking train tickets, financial strain from lost wages, and elderly caregivers struggling with long-distance travel. Since cleft treatment is a multi-stage process extending over several years, some patients eventually drop out due to a lack of ongoing support, making accessibility an ongoing challenge.

Hospital capacity remains a pressing concern, with bed availability growing increasingly limited due to the high patient load. Despite performing nearly 400 surgeries annually, the hospital has only one general ward dedicated to cleft patients, leading to space constraints and competition among specialists for bed allocations. Seasonal pediatric cases, such as diarrhea and pneumonia, further strain hospital resources, intensifying the difficulty of patient management.

Speech therapy also presents significant hurdles, as dialects in Karnataka change roughly every 50 km, complicating communication between therapists and patients. Most speech therapists at RMH are from Kerala and have only basic Kannada proficiency, making it difficult for them to adapt to regional linguistic differences. This language barrier reduces therapy effectiveness, as clear communication between therapists and patients is essential for speech development. Additionally, budget constraints prevent the hiring of senior local speech therapists, whose fees exceed RMH's allocated resources, further restricting access to specialized speech therapy.

Despite excellent medical infrastructure, support systems, and the availability of essential medicines, logistical challenges continue to pose significant barriers to care.

Identifying sustainable solutions will be crucial for ensuring treatment continuity, improving patient retention, and strengthening long-term cleft care outcomes.

Dr Vijay Kumar-Hyderabad Centre:

The Hyderabad Centre handles approximately 200 cases each year. According to Dr. Vijay, the occurrence of combined cleft lip and palate cases is gradually declining, while instances of isolated cleft lip and palate are becoming more common.

An emerging concern is that around 20% of isolated cleft palate cases also present with cardiac issues, which warrants further investigation. Another key area requiring attention is speech therapy, as optimizing its effectiveness remains a challenge. Ideally, patients should attend weekly sessions at the beginning, gradually reducing the frequency as they progress. However, for those traveling from distant locations, maintaining consistency in therapy becomes difficult, leading to missed sessions.

Efforts were made to introduce online speech therapy, but several obstacles persist. Many families do not own smartphones, or they have only one phone, which the father takes to work. Limited internet access, household responsibilities, lack of cooperation from the child, and low parental awareness and ability to facilitate therapy at home further complicate the process. Overcoming these challenges remains essential to ensuring proper speech development for affected children.

Dr Ujwala Dahiphale-Aurangabad Centre:

The number of such patients continues to remain high, with various contributing factors such as consanguineous marriage, genetic predisposition, heredity, nutritional deficiencies, the mother's age (whether too young or too old), and a high number of previous pregnancies.

As a doctor, she is committed to treating all types of deformities, but financial constraints limit her ability to provide comprehensive care. For instance, many patients suffer from fistulas, a secondary complication following palate surgery. However, the program has a strict limit on the number of fistula surgeries allowed, as its primary focus is on addressing the initial problem. Unfortunately, if a fistula remains untreated, it can lead to speech impairments and other complications, ultimately reducing the overall success

rate of the treatment. Patients with bilateral lip and palate conditions are particularly prone to developing fistulas.

In some cases, she refers such patients to government hospitals for treatment, but trauma patients are given priority there, causing delays for those needing elective fistula surgery. Additionally, the Centre does not provide speech therapy, and obtaining it externally can be prohibitively expensive, costing around ₹800–₹1,000 per session—an amount many patients cannot afford. Dr. Dahiphale does her best to compensate by counseling parents, but it does not always yield the desired results.

The same challenges exist for dental care, which palate patients also require but is not available at the Centre. Patients must seek treatment elsewhere and pay for it themselves. While Dr. Dahiphale occasionally asks her colleagues to offer free dental treatment, this arrangement cannot be consistently relied upon.

Last year, she successfully performed 84 surgeries, but the number has dropped to 40 for 2025–26, leaving many patients who rely on free treatment without access. Furthermore, if a hospital is partnered with ABMSS, it cannot receive funding from any other organization for cleft surgeries or related services. While SmileTrain does provide free cleft surgeries, its support is limited to surgical procedures, leaving patients without the comprehensive care they require.

Her primary concern is ensuring that the children she operates on receive additional essential treatments, particularly for fistulas and dental care. However, obtaining approval for fistula surgeries from ABMSS takes time, preventing her from giving patients a clear timeline for further procedures. This uncertainty often results in families losing motivation and disengaging from follow-up care, further delaying treatment.

Another significant challenge is anesthesia, which poses heightened risks due to the young age of the patients. Dr. Dahiphale is willing to operate on as many patients as possible, but she must seek permission to perform additional surgeries beyond the allocated number. Her hospital has a strict mandate that all cleft patients receive free treatment, ensuring that no charges are imposed on them.

ANNEXURE-3: IMPACT STORIES - PATIENT FAMILIES' INTERVIEWS

KOLKATA:

1. Ambiya Khatun

Surgeries & Missed Therapy:

Eight-year-old Ambiya from Devraspur had her first surgery at Jain Trust Hospital while attending Anganwadi. Since then, she has undergone four surgeries at Narayana Hospital over the past four to five years. Unfortunately, she missed speech therapy due to her mother's spinal fracture and her father's inability to take time off work.

Family & Diagnosis:

The youngest of four sisters, Ambiya's condition was a shock, as her mother had no prior knowledge of it before delivery. She received no prenatal support from government health centers, as assistance stops after the second child. Despite societal stigma, her family supported her instead of blaming her.

Treatment & Support:

Her mother learned about free surgeries through a friend and an outreach camp in her village. A field coordinator guided them through the process, convincing the family to proceed with treatment. Speech therapy has been part of her care, and dental treatment will follow once surgeries are completed.

Challenges & Education:

Traveling four hours to Kolkata for treatment was stressful for her mother, who has limited education (up to 7th grade). She remains committed to her daughters' education—Ambiya is in 3rd grade, while her older sisters are in 7th, 10th, and 12th.

Impact & Outlook:

Surgery has greatly improved Ambiya's appearance, making eating easier and enhancing her speech clarity. Her mother hopes this will benefit her future social integration and marriage prospects.

Gratitude & Program Awareness:

The family is deeply appreciative of the free treatment, which also covered travel and food expenses. Without this support, they could not have afforded the surgeries. Though unaware of the funding source, they now understand it is a non-governmental initiative rather than a state program.

2. Afroja Khatun

Early Diagnosis & Treatment Discovery:

Afroja, nearly three years old, is a twin born with a cleft condition and a low birth weight of 1.7 kg. Her father and grandmother, concerned about her health, sought treatment after meeting a field coordinator on a train who informed them about free cleft surgeries.

Feeding Challenges & Surgeries:

Due to swallowing difficulties, Afroja couldn't breastfeed or drink from a bottle, requiring spoon-feeding. Seeing another child's successful surgery gave them hope. She underwent two surgeries so far, with more treatments ahead, including speech therapy, dental procedures, and a bone graft before dental work begins.

Impact & Financial Concerns:

Her father is relieved that she will be able to speak. He acknowledges that without free treatment, they couldn't have afforded the surgeries. Government hospitals have long waiting lists, which would have caused financial strain due to missed workdays.

Support & Gratitude:

Travel assistance and food coupons made hospital visits easier. As a daily wage worker in the bidi industry, such support was invaluable. However, working from home exposes the family, including Afroja's mother during pregnancy, to tobacco.

Outlook:

Though the family doesn't know the funding source for the surgeries, they are immensely grateful for the help, recognizing that without it, Afroja's treatment would have been impossible.

3. Pratay Samanto

Diagnosis & Early Challenges:

Born on December 22, 2022, Pratay was diagnosed with cleft palate, though he did not have a cleft lip. Doctors advised surgery once he reached 10 kg. His parents, overwhelmed as first-time parents, struggled to find proper care until they learned about free treatment at Jain Trust Hospital. Feeding was difficult, with milk and food leaking through his nose, requiring spoon-feeding for eight months.

Financial & Treatment Access:

His parents were unaware of the high treatment costs, estimated at ₹2 lakh in private hospitals. Living two hours from Kolkata, they found crucial support through the hospital's outreach, including communication from Bengaluru. Speech therapy is ongoing, and the parents are committed to every session. His father is a farm laborer, and his mother contributes as much as possible.

Post-Surgery Improvements:

Within 10 days after surgery, his speech showed remarkable progress—he now speaks instead of relying on gestures. His parents encourage him to articulate his needs, though he still requires help with certain words.

Family Struggles & Sacrifices:

Before his birth, his mother suffered a kidney infection, requiring surgery that forced them to sell their land. Doctors advised waiting six months before conceiving, but he was conceived earlier, leading his father to reflect on that decision.

Gratitude & Support:

His father is deeply thankful for the free treatment, acknowledging that without financial aid, they could not have managed the surgeries. Although unaware of the funding source, they remain grateful for the support that changed their son's life.

4. Alina Khatun

Shabana's daughter, Alina, is 22 months old and has two siblings—a sister and a brother. Shabana only learned about Alina's cleft condition after her birth, which came as a shock. In many cases, mothers are unfairly blamed for such circumstances, but she is grateful for her family's support. Her sister-in-law accompanies her on hospital visits, offering reassurance through the process.

Treatment:

Shabana discovered the treatment centre at Narayana Hospital through an identification camp held in her village. She obtained the contact information there and travelled to Kolkata to seek treatment for Alina. When she first reached out to the centre, her baby was just three months old. Doctors informed her that Alina needed to weigh at least 5.5 kg, advising her to return when she was six months old. Due to the gap in her palate, Alina was unable to suckle, so Shabana fed her milk using a spoon. Using a bottle was not an option, as the milk would leak through her nose, causing her to choke.

At six months old, Alina underwent her first surgery, which repaired her lip. Later, a second surgery was performed on her palate. Shabana

received pre- and post-surgery counselling, where doctors thoroughly explained the procedure and her role in supporting her daughter's recovery.

Speech:

Now, Alina is slowly beginning to speak, forming words here and there. Children with cleft conditions require speech therapy alongside surgery to help them articulate sounds correctly. She is currently undergoing therapy to aid her communication skills.

Impact:

For Shabana, the most significant change after surgery is that Alina looks better and can eat properly. She is committed to completing every treatment and following the doctor's recommendations so her daughter can live as normally as possible.

Shabana did not have to spend anything on the treatment, including food or travel expenses. Although she does not know the donor, she feels deeply grateful for the financial support, which has been a blessing for families like hers who otherwise could not afford the cost. Her husband, a construction worker on daily wages, would have struggled immensely to gather the necessary funds. She expresses heartfelt gratitude to the surgeon and the hospital staff for their unwavering support.

5. Rehan Haider

Birth & Discovery:

Rehan Haider was born on September 16, 2023. During her pregnancy, his mother underwent sonography, but she was not informed beforehand that her baby had a cleft condition. As her first child, seeing Rehan with a cleft lip and palate was an unexpected shock. While her in-laws did not directly blame her, they implied that she should have taken better precautions during her pregnancy.

Surgery & Treatment:

Rehan underwent surgery at six months old to repair his lip, followed by another operation at nine months to address his palate. His father works in a hotel in Bengaluru, while his mother resides in their village with her in-laws. For the hospital visit, she traveled a considerable distance—about three hours—with her father-in-law to attend an interview.

Hospital Connection:

She learned about Narayana Hospital through her neighbours, who knew someone who had previously received treatment there. They provided her with the contact details, which led her to seek care for her son. No one in her family or village has this condition. She mentions that she is not married within close relations, a practice commonly followed in their community, so that also could not be a reason for a cleft child.

Post-Surgery Improvements:

For her, the most significant improvement after the surgery is Rehan's appearance. Additionally, he can now eat properly. Though he speaks only a little for now, they remain hopeful that he will catch up with time. She is committed to completing the necessary treatment to support his development.

6. Father and Daughter's Journey

Condition & Identification:

A father and his daughter both had cleft conditions—he had only a cleft lip, while his daughter had both a cleft lip and palate. A social worker encountered them and brought them to the hospital. Patients are typically identified through camps, as many struggle to find the right treatment on their own. The outreach team distributes around 10,000 pamphlets in each region before conducting identification camps, which primarily attract those in need of treatment.

Reluctance & Encouragement:

Initially, the father was hesitant to undergo surgery, but the medical team encouraged him, and his wife also persuaded him to proceed. Their family was reluctant to approve surgery for their child. After the procedures, they admitted that both look better.

Community Trust Issues:

The surgeon noted that people are often skeptical about free surgeries, fearing hidden motives behind such expensive procedures—especially since the hospital is corporate-run. The medical team works to overcome these trust barriers.

Post-Surgery Transformation:

The father expressed that his life has completely changed. Once diffident, he now feels confident, and his self-image has significantly improved. His mistrust of the system has faded, and he is committed to ensuring his daughter completes her treatment.

Future Priorities:

For both parents, their foremost goal is integrating their daughter into society as she grows. Once she is settled, they will consider her marriage.

PUNE:

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1) Ved Gawade

Early Diagnosis & Decision:

Ved, now four years old, was diagnosed with clubbed feet in the third month of pregnancy and a cleft condition in the fifth month. Despite these findings, his parents decided to continue the pregnancy, reassured that both conditions could be corrected through surgery.

Surgeries & Treatment:

His first surgery was performed at Sai Shree Hospital under the ABMSS project when he was two years old. His mother learned about the treatment through a representative visiting their village. So far, he has undergone three surgeries, including one for his foot. He wears special shoes, but his foot still twists while walking. He is homeschooled instead of attending regular school.

Feeding Challenges & Solutions:

Feeding him for two years with a cleft in the roof of his mouth was difficult, as he would frequently throw up milk. Aundh Government Hospital provided a clip that was inserted in his mouth, making feeding easier and helping him gain weight. His surgery was delayed due to low weight, but the intervention helped him progress.

Family & Commitment:

Ved's parents have studied up to the 10th standard. His father works as a driver, while his mother cares for him and manages the household. Their priority has always been securing treatment for their child, and they have decided not to have another child.

Speech Development & Future Procedures:

The biggest impact of surgery is that Ved can now speak. His parents took lessons and practiced speech exercises with him at home. His tongue is stuck to the bottom of his mouth, limiting movement, which became apparent only after he started speaking. A minor surgery, lasting about 15 minutes, will soon correct this issue. He had no skin on the roof of his mouth and required a skin graft.

Financial Relief:

With multiple surgeries and ongoing treatment, financial support has been a tremendous relief for the family. They are deeply grateful for the assistance, which has alleviated the burden of managing expenses for his care.

2) Tanuja Samgir

Background & Treatment:

Tanuja, 17 years old, is able to share her experiences firsthand. She underwent two surgeries at Birla Hospital, the first performed by Dr. Jangam in 2022 at age 14. She learned about the treatment through an identification camp in her village, where a coordinator provided her with information and contacts.

Previous Surgeries & Future Treatment:

Before coming to Birla Hospital, she had already undergone two surgeries in childhood, including rhinoplasty, both of which were free. Further dental treatment will be required.

Breathing & Plastic Surgery:

She previously struggled with breathing issues, which were resolved after surgeries by Dr. Jangam. However, one of her nostrils is positioned inward, flattening one side of her nose. Plastic surgery is planned to further improve her breathing.

Education & Family:

Tanuja is from Veer Village and traveled independently for her interview. Having recently passed her 12th grade; she plans to pursue a degree in computer science. Her younger sibling does not have a cleft condition, though her maternal aunt had a cleft lip.

3) Faisal Sayyad

Diagnosis & Acceptance:

Faisal, now two and a half years old, underwent surgery a year ago. His mother learned about his cleft lip during the fifth month of pregnancy but decided to proceed, accepting the condition. He is their first child.

Birth & Early Challenges:

His mother delivered in Daund but was advised to take him to Aundh Hospital, Pune, as they were not equipped to handle his condition. He was kept in the ICU for six days due to feeding difficulties, where doctors provided a cleft clip to help him feed.

Treatment & Surgeries:

They were informed about Birla Hospital, where cleft surgeries are performed free of cost. Faisal underwent his first surgery at one year old, followed by a second one recently. Doctors have advised that more surgeries will be needed.

Speech & Other Conditions:

He speaks with a lisp, but his parents understand him well. In addition to his cleft condition, he has club toes in one foot and fused fingers in one hand, which will also require surgical correction. His parents were knew about these issues during pregnancy.

Financial Relief & Family Outlook:

The free surgeries have been a major relief, covering medical, food, and travel expenses for the mother. Despite choosing to continue the pregnancy, his parents were anxious about his future. After his first surgery, the family felt reassured seeing his improved appearance. His mother, who studied up to the ninth grade, and his father, a scrap dealer with a seventh-grade education, have limited financial prospects. However, they are deeply grateful for the support that has eased their burden.

4) Sabrina Inamdar

Early Diagnosis & Acceptance:

Sabrina, now three years old, underwent her first surgery at the age of one. Despite the surgery, she still struggles to speak, managing only a few words. Her seven-year-old sister does not have this condition, though a relative on her mother's side had it.

Family & Social Challenges:

Her mother learned about the cleft in the fifth month of pregnancy and accepted it as God's will. She holds an ITI diploma and previously worked at Tata Motors but was not permitted to work after marriage. Her husband, who has completed 12th grade, runs a chicken shop. His family opposed her employment.

Discovering Treatment:

There were several children with cleft conditions in her area. She learned about free surgeries at an outreach camp held in her village, Belha.

Cultural & Familial Pressure:

As one of four siblings, her parents pressured her into marrying someone less educated due to societal expectations. Her in-laws were unhappy about her giving birth to a second daughter, particularly one with a cleft, and questioned why she didn't terminate the pregnancy. She firmly stood by her decision, insisting she was fine with having another daughter.

Further Treatment & Progress:

Sabrina requires another surgery, which is expected to improve her speech. Financial support has been invaluable, easing the burden of treatment costs. During sonography, doctors reassured the parents that free surgeries were available for such conditions.

Current Condition:

Despite her speech challenges, Sabrina is able to eat all types of food. Her family has gradually come to accept her condition, especially after seeing improvements following surgery.

5) Bhumi Abnave

Bhumi, a 7-year-old girl, was born with a cleft palate, though her lips remained unaffected. Her mother was unaware of the condition, as isolated cleft palates are challenging to detect through sonography during pregnancy. It wasn't until the COVID-19 pandemic that they noticed Bhumi was struggling with speech, and the condition had gone undiagnosed until then. Upon consulting a doctor, she was referred for surgery.

The news of Bhumi's condition was overwhelming for her mother, who fainted in the hospital upon learning about it. Bhumi's first surgery took place at Bharati Vidyapeeth Hospital in 2022 but was unsuccessful. Later, she came across a newspaper advertisement for cleft surgeries at Birla Hospital and reached out using the contact details provided.

Bhumi's mother, a graduate, works in a bank, while her father is employed as a driver in a company. She has a 14-year-old older sister. Some family members unfairly blamed the condition on inadequate prenatal care. However, since Bhumi does not have a cleft lip, her appearance is normal. The primary challenge she faces is speech—she lisps and struggles to form continuous sentences. Every morning, her mother assists her with speaking lessons.

Further treatment, such as bone grafting, may be necessary. While her mother did not incur any expenses at Birla Hospital or with Dr. Jangam, she spent approximately Rs. 50,000 at Bharati Hospital on diagnostic tests and the initial surgery. For someone who has already borne significant medical costs, free follow-up surgeries are a blessing and a much-needed relief from financial concerns.

6) Shrijay Kalbhor

Two-year-old Shrijay has undergone two surgeries so far—the first for his lip at four months old and the second for his palate a year ago. An Anganwadi teacher referred the mother to Aundh Hospital, where she initially sought treatment. From there, they were

directed to this hospital. She has been informed that further treatment, including bone grafting, may be required.

She was aware of her baby's cleft condition in the fourth month of pregnancy. Having already undergone C-sections for her two older daughters, she was no stranger to medical challenges. However, some family members irrationally blamed the deformity on her having watched an eclipse. She decided to keep the baby as the doctor had informed that the cleft could be corrected by surgery.

She got married just a year before completing her graduation. Her husband is a farmer, cultivating his own five-acre land in Loni Kalbhor. When asked if they could have raised funds for the surgeries, she recalled her aunt's assurance that everything is free for farmers. This gave her confidence that Shrijay's surgeries would be covered without financial burden.

7) Palak Rathi

Her daughter, born with a cleft lip and palate, is one of a pair of twins, the other being a son. She was born prematurely, weighing only 950 grams, and had to be kept in an incubator for 50 days. Her twin brother faced intestinal issues that prevented him from passing stools, requiring surgery at just 15 days old. As a result, his growth has been slower than his sister's. Although the surgery helped, he continues to struggle with bowel movements, which should improve as he gains strength.

The parents were aware of one twin's cleft condition but had assumed the other would be fine. The overwhelming medical challenges were stressful, but they never considered terminating the pregnancy. Determined to face whatever came their way, they found reassurance in their gynecologist's advice that the cleft could be corrected through surgery.

They extensively researched treatment options before approaching Dr. Jangam, seeking a highly skilled surgeon. A dentist they consulted recommended a hospital accustomed to complex surgeries and directed them to this facility. Before contacting Dr. Jangam,

they were unaware that free surgeries were available. However, after meeting him, they felt reassured that he was the right choice, and their trust has been validated. When their daughter turns 10, she will undergo further treatment, including bone grafting and orthodontics.

One of the most significant improvements has been her ability to eat. Previously, food would escape through her nose, but that issue has now been completely resolved. Her speech has also improved noticeably.

The mother left her job upon discovering she was pregnant with twins. Both parents are well-educated. The father has a good job at L&T. Although financially stable, the premature birth of the twins, their extended stays in the NICU, and multiple surgeries have placed a substantial financial burden on the family. With only one earning member, the support provided through this project has been a much-needed relief and blessing.

8) Devansh Shingade

Four-year-old Devansh was born with a cleft lip. His parents only became aware of the condition in the eighth month of pregnancy, making it a shock to see him after birth.

However, their doctor reassured them that surgery was an option and would help restore his appearance. Originally from Rajgurunagar, about 40 km from Pune, the family learned about the treatment facility through an Anganwadi teacher, who also informed them that the surgery would be free. Following her advice, they reached out to Dr. Jangam for assistance. Devansh has two older sisters. For his parents, the most significant impact of the surgery has been seeing their son look better, bringing them immense relief.

9) Manjiri Magare

Manjiri is 14 years old. She had both-lip and palate cleft.She had her first surgery when she was 6 months old at Dahiphale Hospital in Sambhajinagar. Her palate surgery was done at Hedgewar Hospital when she was 4 years old. She says the latest surgery has

made a big difference in her speech. Currently, her dental treatment is going on here and she is wearing a clip. She says that if she removes it, her speech becomes clearer. She will need rhinoplasty going forward. She says she never had any problem in school about teasing or anything.

10) Abhishek Tiruva

Abhishek is 16 months old. His father is a supervisor in a paying guest house. It's a big guesthouse with 90 odd guests from IT sector staying there. He with his wife and child lives there and takes care of operations. They had been told about the disorder during pregnancy. In fact, the doctor had also said that the child might have clubbed feet or hands. But we decided to keep it despite all the warnings.

Fortunately, his hands and feet were ok. He only had cleft lip and palate. They faced a lot of trouble when he was an infant. First, they went to Sassoon. But when they saw the long queues, they thought that they could not deal with so much crowd. He could not get that much leave from his job. When they were coming back from Sassoon, they met one of the staff members from Birla Hospital. He did not believe when she said the treatment would be free. When he saw the board outside, he finally really believed it. They got all the information and guidance from Dr Jangam, to whom they are grateful.

11) Common Sharing by Parents

Samarth's mother left school in the 5th to look after her siblings. She was married off at the age of 17 by her parents and is now herself a mother of three at the age of 24. Her youngest and only son has cleft lip and palate. She shared that she had taken her son to Dagdushet Halwai Ganesh Temple for blessings, when the priest told her to go to Dr Jangam at Birla Hospital. He also gave them a letter of reference. Since he had only cleft lip, there was not much difficulty in feeding him.

Shrotibha's mother said that they knew about the cleft lip in the 8th month of pregnancy. Nobody in the family had this disorder. She is their only child. She had both – lip and palate disorder. Her lip was corrected when she was four months old and then palate

surgery came at one year age. They have migrated from Haryana to Pune for work. The father tried to find out where such surgeries are conducted and found out the address.

One of the mother who had come from Alandi, said that whatever the cost, they would have tried to raise the money for surgeries if they were not free. She said they were prepared and not afraid or anxious when the child was born. She is also married to her maternal cousin which means consanguineous marriage. This is one of the major causes contributing to cleft lip and palate disorder.

One mother shared that when her family learned about the cleft condition during her pregnancy, they urged her to terminate. However, she and her husband remained steadfast in their decision, choosing to welcome their baby despite the pressure.

Finding Treatment:

Families from Solapur and Satara learned about cleft treatment through Anganwadi teachers, who informed them about visiting specialists from Birla Hospital, Pune. Following the recommendations, they travelled to Pune, where their children underwent surgeries.

Surgery & Recovery:

One parent from Satara shared that her son had only a cleft palate and was unable to speak before surgery. After the operation, he started speaking. A mother from Chinchwad, whose daughter underwent cleft surgery at four months old, was later advised by a dentist to seek additional treatment at Birla Hospital for advanced procedures like bone grafting and jaw correction. She herself also has a cleft lip. Another parent recounted that three surgeries had already been performed on her son, with two more needed. His treatment will continue step-by-step until he turns 15.

Financial Concerns:

Parents who consulted private hospitals were shocked at the cost of treatment, estimated between ₹10-15 lakh. Many feared lifelong debt, unsure how they could afford care for their child. Some families did not realize free treatment was available and had previously raised substantial amounts for surgeries. One parent spent ₹2.8 lakh for an operation, unaware of free services.

Early Challenges:

Several parents struggled to feed their children due to cleft conditions. Food would leak through the nose, causing difficulty. In Aundh Hospital, doctors provided a special mouth clip that helped an infant drink milk more easily.

Lack of Awareness:

Some parents did not recognize cleft palate in their children until much later. One mother noticed a gap in her child's mouth after he turned a year old. Few parents were aware of the multiple surgeries required or additional treatments like speech therapy and orthodontics. Most doctors reassured them that cleft could be corrected through surgery, though they did not always explain the full course of treatment. Sonography can detect cleft lips in pregnancy, but cleft palates are often missed.

Relief & Gratitude:

Families who accessed free surgeries at Birla Hospital expressed deep appreciation. The financial support saved them from immense stress and uncertainty. None of the parents

had to pay for surgery, other treatments, travel, or food. Additionally, meals for one accompanying person were provided free of charge. While some parents stated they would have managed to raise funds if necessary, all were profoundly grateful for the assistance, which eased their burden and relieved them of the anxiety of repayment.

Impact:

The most significant impact for families is seeing their child looks better and eats properly after surgery. Many also value the child's ability to speak, attend a regular school, and socialize with friends, which greatly improves their confidence and integration into society.

Pandharpur:

1) Shivam Shendage

The mother had visited a temple where she encountered someone who had seen a child with a similar condition. It was through this conversation that she learned about the free surgeries offered by Nelson Hospital in Pandharpur, which led her to seek treatment there. The family hails from Taratgaon in Pandharpur Taluka and has a consanguineous marriage. Her son was also born blind in one eye. Both of these conditions were detected during the pregnancy. His father also had a cleft lip, which was operated on at the age of 25 by Dr. Jangam. The father has completed his education up to the 12th grade, while the mother studied until the 8th grade. He is a farmer. Dr. Jangam has suggested that a prosthetic eye could be an option for the child, which would be another major surgery.

Now, their son is undergoing treatment for his cleft condition, once again under Dr. Jangam's care. Surgery for cleft lip correction in adulthood typically has a success rate of 50% to 60%. The child is currently two and a half years old, and the family has also

welcomed a daughter. Given the hereditary nature of the condition, the next generation may face similar risks.

The boy has already undergone two surgeries—one for cleft lip and another for cleft palate—and will require bone grafting at the age of eight. The mother shared that, since his father had the same condition, they were confident it could be treated. However, the blindness in one eye was unexpected, and they had not sought any medical opinions for it earlier. The family places their full trust in Dr. Jangam and believes he will provide the necessary treatment. The mother also expressed that, had the surgery not been free, they would have found a way to raise the money to ensure their son received the care he needed.

2) Mahadevi Hiparkar

Mahadevi's mother, who hails from Barshi, shared that a nurse at the hospital where she delivered her daughter had recommended Nelson Hospital for treatment. A sonography performed during the fourth month of pregnancy had revealed the cleft condition. However, the doctor merely informed them of its presence without mentioning that it could be corrected through surgery. Despite this, they chose to continue with the pregnancy. Mahadevi is their only child so far. She was six months old when she underwent surgery to correct her cleft lip. Unlike some cases, she has a cleft lip but not a cleft palate. When she turns eight, she will require a bone graft procedure.

The family speculated that certain medications the mother had taken might have contributed to the condition. Initially, they were overwhelmed by fear and uncertainty about how to navigate the situation. However, after meeting Dr. Jangam, their confidence grew, and they became reassured that their daughter would receive the care she needed.

Mahadevi's father is an uneducated farmer, while her mother completed her education up to the tenth grade. Despite their challenges, they are committed to ensuring their daughter gets the necessary treatment and support.

3) Akshara Shivsharan

Three-year-old Akshara was born with a cleft palate and underwent surgery two years ago. Her parents first noticed something was wrong when she was just a month old—milk would come out of her nose while feeding. Concerned, they took her to Solapur, where the doctor informed them that she would need surgery, estimating the cost to be between ₹80,000 and ₹90,000.

Determined to find the best possible care for their daughter, Akshara's father turned to YouTube, where he discovered Nelson Hospital and Dr. Jangam. That led them to seek treatment there. Akshara has a five-year-old brother who does not have any medical issues. Since her condition was limited to the cleft palate, her appearance remained unaffected.

For the family, the biggest relief has been seeing her eat properly, something they had struggled with in the early months. They are grateful for the medical intervention that has helped Akshara live a more comfortable and healthy life. Parents, being agricultural labourers, would not have been easily able to raise funds for the surgeries.

4) Devraj Javir

Devraj is four years old. His parents first learned about his cleft condition during a sonography in the sixth month of pregnancy. Having never encountered a cleft case before, they were surprised—he was the first child with this condition not only in their family but in their entire village. The doctor reassured them that surgery would correct the condition and informed them that the procedure would be free. He also referred them to Dr. Sagar Jangam for further treatment.

Devraj did not face any difficulties with breastfeeding, thanks to his mother's sister, a nurse, who guided her on how to position him correctly. However, when they attempted to feed him with a spoon, the milk would come out of his nose due to the horizontal posture. For the family, the most noticeable impact of the surgery has been in his appearance, which has significantly improved thanks to medical intervention. His father

is an agricultural labourer and would have found it extremely difficult to raise money for the surgeries.

5) Bharati Karade

Bharati, now 14 years old, underwent her first two surgeries at Poona Hospital, both of which were provided free of charge under the SmileTrain program. The doctors had informed her parents that she would require three to four surgeries at different stages of her development. When they sought the third surgery, her haemoglobin levels were too low, and they were advised to return later. Despite making multiple trips to Pune, they were repeatedly told to come back the following month. Eventually, they lost hope and stopped pursuing treatment there.

Later, they learned that Dr. Jangam also performed surgeries in Pandharpur, leading them to Nelson Hospital, where Bharati underwent bone grafting. Her father, a farmer, has observed significant improvement in her speech—it is much clearer now—and her voice quality has also enhanced. He believes that once she completes her dental treatment, her speech will improve even further. For Bharati, the most significant change has been her ability to speak properly and the freedom from other complications, making a profound difference in her daily life. She is in the 9th grade and hoping to be a teacher one day.

6) Supriya Mhaske

Supriya, now five years old, was born with both a cleft lip and palate. She has undergone three surgeries, all performed by Dr. Jangam. Her parents learned about her cleft lip during the seventh month of pregnancy, but by then, termination was no longer an option. At birth, she weighed only one kilogram.

Her first surgery took place when she was two years old. Due to her palate condition, she was fed only milk for several months. The doctor recommended nutritional supplements, which her parents purchased from a medical store, helping her gain enough weight to undergo surgery. It was only after her palate surgery that she could start eating

solid food. Because her soft palate remained open, the procedure had to be performed twice.

Supriya is her parents' fourth child—the first three are boys. They had long wished for a daughter, and she became the first girl in their extended family. Her father, a laborer, struggles to support such a large family on his limited income. Without free medical care, these surgeries would have been beyond their reach.

For her father, the most significant improvements have been in Supriya's appearance, speech, and ability to eat properly. Previously, she would cry constantly due to hunger, but that distress has now disappeared. She will also require bone grafting and speech therapy to further enhance her communication skills.

7) Shreya Chopade

Eleven-year-old Shreya recently underwent bone grafting. Her earlier lip and palate surgeries were performed in Latur when she was an infant. She has a four-year-old younger brother who does not have any medical issues. Her father's family had previously encountered this condition, and a relative had successfully undergone corrective surgery, so they were aware that treatment was possible.

However, during her mother's pregnancy, the sonography did not indicate the condition, making it a shock when Shreya was born. Feeding her proved challenging, as she struggled to swallow milk easily. Following their doctor's advice, they fed her using a dropper, administering small quantities frequently to ensure she received adequate nutrition.

Her first two surgeries took place when she was nine months old in Latur, provided free of charge. The doctors had informed them that additional procedures would be required. Later, a relative told them about Nelson Hospital in Pandharpur, which was much closer to their home. They decided to seek treatment there. Last year, Shreya underwent bone grafting at Nelson Hospital.

Her father shared that both surgeries were successful. The first procedure helped normalize her lip appearance, while the second significantly improved her ability to eat and speak. She can now communicate clearly, even answering questions with ease.

Although they would have made every effort to gather funds if the surgeries had not been free, the financial support made a huge difference in their ability to access care. Her father, a farmer, manages ten acres of irrigated land to support their family.

Aurangabad:

1) Swara Jadhav

The parents did not realize Swara had cleft palate till she was almost a year old. She was suffering from cold constantly. One of their relatives noticed the hole in the roof of her mouth and she showed it to her parents. Finally, they took her to a doctor who diagnosed her with cleft palate. That is when they got the surgery done from a doctor in Yevala. She is three years old now. They paid Rs 40,000 for the first surgery. Later she developed fistula. By then, they came to know about Dahiphale Hospital in Aurangabad where they came for this surgery. Some relatives had consulted Dr Dahiphale and gave the contact to Swara's parents. Swara has two older sisters. Her father thinks the surgery is successful because she is able to speak better and also the food coming out of her nose has stopped. Her voice has also changed. She is not suffering from cold anymore. They only had to spend on the travel to the hospital, otherwise they had spent nothing. Dr Dahiphale instructs the parents on how to take speech sessions and other exercises to increase the muscle strength in her mouth.

2) Kavish Chavan

Kavish is three years old and has already undergone both lip and palate repair surgeries. His family learned about the hospital's expertise in cleft surgeries when his uncle, who had spinal surgery at Dahiphale Hospital, recommended it. They discovered the cleft during the third ultrasound in the seventh month of pregnancy—a finding that left no

viable alternative but to plan for postnatal treatment. Kavish was born at a government hospital, where the medical team advised his family to seek treatment there.

His first surgery was performed at nine months, and the second at thirteen months. Initially, because he was unable to suck from a bottle, Kavish was fed milk with a spoon; however, following his first surgery, he was able to transition to bottle feeding. The family comes from Kannad village in the Sambhajinagar district. His father, a farmer with six acres of land who studied up to the tenth standard, is immensely grateful, especially since the surgeries were provided free of cost and every aspect of the treatment was explained clearly. Meanwhile, Kavish has a younger brother who is unaffected by the condition.

3) Aryan Ingale

Aryan, a 12-year-old seventh grader, was born with a cleft lip. His surgery took place a year ago, significantly improving his appearance and boosting his confidence. Before the operation, he was often teased by his classmates, though his speech was largely unaffected since he only had a cleft lip. Both Aryan and his parents are happy with the results.

His father had first taken him to Jalgaon when Aryan was four months old, but due to a cold, the surgery was postponed, and he didn't return for treatment at that time. Another child from their village had undergone a similar procedure, and their family had shared information about it, but since Aryan was still an infant, his father didn't act on it. When Aryan was about six or seven years old, his persistent cold and cough prompted his father to seek treatment. Through an online search, he found out about this hospital. He first brought Aryan for treatment a couple of years ago, but since Aryan had a cold at the time, he was advised to return later. About a year ago, when Aryan was in better health, the surgery was successfully performed.

The operation not only improved Aryan's appearance but also completely cured his chronic cold and cough. He now speaks clearly and confidently. Previously, he was extremely self-conscious about his slurred speech—avoiding interaction with other

children, hesitating to travel, and even refraining from speaking altogether. After the surgery, he has gained remarkable confidence.

Aryan's father works as a traveling salesman for Bentex jewelry, which kept him occupied and contributed to the delay in seeking treatment earlier. He has limited education, just enough to read and write. The family was not informed about the cleft during prenatal sonography.

4) Viraj Kapse

Viraj, now 28 months old, comes from Ahilyanagar. He underwent palate surgery in 2023 at the age of 10 months. His mother first noticed something was wrong when he struggled to breastfeed after birth—choking and having trouble breathing. Concerned, his parents rushed him to a hospital, where they were informed about his cleft condition. They stayed there overnight before transferring him to Karmala.

At Karmala, Viraj was hospitalized for 15 days. Initially, he was fed through a tube, and later, his mother was advised to feed him with a spoon—a practice they continued until his surgery. The procedure has dramatically improved his ability to eat, and today, he can consume all types of food. Though he has been slightly delayed in speaking, he is now able to articulate two-letter words.

Viraj has two older sisters, both unaffected by the condition. His father is a farmer, and both parents have only basic education. Their marriage is not consanguineous. One of the most significant improvements after surgery has been in Viraj's speech—his voice is much clearer, and his previous snoring has stopped.

Financially, the family would have struggled to afford the surgery had it not been provided free of cost. Viraj's grandfather is battling terminal cancer, and his grandmother suffers from a heart condition, making medical expenses a heavy burden. During Viraj's hospital stay in Karmala, his father fell into deep distress, at times experiencing suicidal thoughts. The doctor counseled him, offering reassurance and support.

An Anganwadi worker with whom he came into contact, told him about a girl she knew who had undergone the same surgery and was now completely fine. Seeking reassurance, he met the girl in person. Seeing her recovered gave him the courage to bring Viraj to this hospital. Now, witnessing his son thrive and grow normally brings him immense relief.

The family traveled 225 km from their village to reach the hospital; a journey filled with hope and determination.

5) Asfaq Shaikh

The child, now two and a half years old, was born with both a cleft lip and palate. His lip surgery was performed at nine months, followed by palate surgery just three months later. Feeding him was challenging at first, but his parents eventually managed by spoon-feeding him.

Although they had undergone prenatal sonography, the doctor never informed them about the cleft. Having never seen a cleft condition before, the sight of their newborn came as a deep shock. Even recalling that moment brings tears to his mother's eyes. The reaction from relatives and friends was cruel—some claimed that if such a child were born to them, they would have killed him. This devastated the mother emotionally.

He was delivered in a government hospital, where doctors directed the family to Civil Hospital for free treatment. A farmer, on whose land his father works, told him about Dahiphale Hospital, reassuring him that the surgery would also be free there. Given the father's occupation as an agricultural laborer, affording the procedure privately would have been nearly impossible.

Despite the painful reactions from their relatives, the success of the lip surgery brought his mother immense relief—her child now looked more typical. His five-year-old sister does not have any health issues. The parents are in a consanguineous marriage, which increases the likelihood of congenital conditions.

6) Anushka Gaikwad

Anushka, now two years old, was born with a cleft lip but no cleft palate, which meant she did not face significant feeding challenges. When she was two months old, her parents took her to a government hospital in Jalna, where the chief doctor advised them to seek treatment from Dr. Dahiphale. He also provided them with a reference letter for her care.

Her parents believe that the surgery has not only improved her appearance but has also helped her speak more clearly. They are highly satisfied with the medical facilities and treatment they received. Her father, who studied until the eighth grade, runs a Pan shop. Anushka has an older brother who is 13 years old and does not have any health concerns.

7) Mohammad Shakir Shaikh

Six-year-old Shakir has undergone surgeries for both his cleft lip and palate. His lip surgery was performed in 2021, followed by the palate surgery in 2023. The two-year gap between procedures occurred because his mother had adopted another child—a daughter—during that time, delaying Shakir's treatment.

Shakir is one of five siblings. After having four sons, his parents adopted his mother's brother's daughter. It was the villagers who provided them with the address for Dahiphale Hospital, leading them to seek treatment there.

His mother left school after the fifth grade, while his father works as a daily wage laborer, making financial resources limited. The opportunity for free surgery has been invaluable to the family.

8) Swaraj Gangawane

Swaraj is a 2nd standard student. He can speak quite clearly. He had bifurcated uvula which was joined by surgery. A doctor in Jalna had told them he would need a surgery and had also said it would cost around Rs 25000. It would have been a struggle to raise the money. The mother is only 8th pass and the father is not even a graduate. They are

farmers. They also have a younger daughter who is okay. At the time of younger daughter, they took care to ensure everything was okay by conducting prenatal sonography.

9) Riyansh Bansod

Riyansh is two and a half years old with both lip and palate disorders. His lip surgery was done at the age of 5 months and palate at the age of 8 months. Both were done at Dahiphale Hospital. His maternal cousin also had similar issue and had got treated here. Though the parent's marriage is not exactly consanguineous, they have genetic heredity. They brought their one-and-a-half-month-old baby here. The doctor assured that surgery would set everything right. They are happy about the entire treatment. They are relieved that he looks better, eats better and speaks better. He is quite comprehensible to the outsiders also. They would have struggled to raise money for treatment. They are farmers with 5-acre land. They have a joint family of two brothers, and they all depend on the land. Both the parents are 12th pass. They have been informed about the future treatment and surgeries. He will need one more surgery for his palate.

10) Gouri Jadhav

Gouri was born with a bilateral cleft lip and palate, both of which were surgically corrected at Dahiphale Hospital. Her first surgery took place at nine months old, followed by the second at the age of four. During this time, her father sent her mother to stay with her parents for a couple of years. Upon her return, the second surgery for her palate was performed. Now, Gouri has come back for treatment of a fistula.

She is the only child conceived after infertility treatment, and her condition is commonly observed in babies born after such treatments or late pregnancies. Her parents, uneducated farmers, believe the biggest improvement is her appearance and her ability to eat comfortably—she no longer experiences food escaping through her nose. The mother has a low IQ and hardly able to look after the child.

11) Sarthak Phatak

Four-and-a-half-year-old Sarthak underwent his first surgery at six months old, followed by palate correction 18 months later. Both procedures were performed at Dahiphale Hospital. His father, a farmer with seven acres of dry land, supports their joint family, which primarily cultivates cotton. Their combined annual income is approximately Rs 1.5 lakh. Despite holding a postgraduate degree, Sarthak's father is married to a woman who studied only up to the 10th grade.

Mr. Phatak's brother, who lives in Paithan, was aware of Dahiphale Hospital and guided them towards treatment. The first surgery made a significant difference—Sarthak was finally able to drink milk. After the palate surgery, he could eat all types of food comfortably. They also have older daughters.

Despite undergoing two or three prenatal sonographies, the doctor did not inform them about Sarthak's cleft lip, a condition that is usually visible during scans. The family experienced mixed emotions—joy at having a son, yet sorrow over his congenital condition. Now that everything is resolved, they feel immense relief. Although the surgeries were free, they were determined to find a way to fund the procedures if necessary.

12) Rudra Pawar

Rudra underwent his first lip surgery at six months old, followed by a second procedure at nine months. Due to a bilateral cleft with a significant gap on one side, the correction had to be performed in two stages. His next surgery will focus on repairing the palate. Fortunately, the cleft in his lip is now barely noticeable.

Prenatal sonography had detected the anomaly, and the doctor reassured the parents that it could be corrected surgically, advising them against termination. Rudra's family has faced considerable challenges—his eldest brother, now nine years old, has cerebral palsy and is unable to move. Their second child was born when the eldest was three but sadly did not survive. Rudra, their third son, was born with a cleft condition.

His father, who left school in eighth grade, works as a helper in a shop, while his mother has completed education up to the 10th grade. Given their financial limitations and their children's medical needs, affording treatment would have been extremely difficult. The parents are in a consanguineous marriage, and Rudra's cousin also suffers from a similar disorder. Through this experience, they have come to the realization that they should not have another child and that close-relative marriages should be avoided for their children's future health.

Bangalore:

1) Janvika Gowda

Janvika was born in the hospital affiliated with ABMSS, where Dr. Jayanth performs all his surgeries. This connection made her parents aware that free cleft surgery would be available for their child. During the fifth-month scan, the cleft condition was detected, but the doctor assured them that the baby was otherwise healthy and advised against termination.

Now four years old, Janvika is their first child. Her first surgery took place when she was four months old, and her parents were informed that she would require multiple procedures over several years. To date, she has undergone four surgeries—initial lip correction, followed by palate surgery. Later, she developed a fistula, which required further intervention. When she turns nine, she will undergo bone grafting.

Dr. Jayanth explained that after palate surgery, a small fistula may develop during the healing process, which must be sealed to improve the child's speech. Although it is a minor procedure, it must be performed under general anesthesia due to the child's young age. The doctor was praising the efforts the mother has put in for her daughter to have normal speech.

Before her first surgery, feeding was difficult, and her mother had to use a special bottle. Afterward, Janvika was able to drink from a normal bottle. Prior to palate surgery, food would escape through her nose, but this issue was resolved with the procedure. Before

the fistula surgery, her speech was nasal, but afterward, she began speaking normally. Her mother diligently follows the speech therapist's exercises to improve her speech.

Janvika has completed nursery and is now moving on to kindergarten, where both her teachers and friends understand her speech. Her mother, a postgraduate, previously worked in a multinational company, while her father, though less educated, is employed in the home loan department of an insurance company. She expressed deep gratitude to Dr. Jayanth and Persistent for funding the program, admitting that they would have had to borrow money if the treatment had not been free.

2) Sidra Khan

Sidra, now two and a half years old, was born with an isolated cleft palate. Since this condition is not easily detectable through prenatal scans, her mother was unaware of it until four days after birth. Upon noticing the issue, her parents immediately sought treatment from Dr. Jayanth, whom they already knew.

Before her surgery at eight months old, feeding was a challenge. Her parents had to use a special bottle, and she frequently experienced vomiting. Fortunately, the surgery resolved these difficulties. She has now started speaking a few words and is undergoing speech therapy to aid her development.

Sidha's mother holds a Bachelor of Commerce degree, while her father, who completed education up to the 10th grade, runs a newly established readymade garment shop. Previously, he worked for others, and raising funds for the surgery would have been difficult. Their older son is healthy and does not have any medical concerns. As they are in a consanguineous marriage, they have become more conscious of genetic risks and plan to be cautious when arranging their children's marriages in the future.

3) Janani

Janani, now two and a half years old, has already undergone three surgeries. She was born in Vanivilas Hospital, the largest government hospital in Bengaluru. Upon birth,

her parents were advised to consult Dr. Jayanth, as government hospitals have a direct referral system with him for cleft-related cases.

Her condition was detected during an eighth-month pregnancy scan, shocking and distressing her family despite reassurances that surgical intervention was possible. The mother recalled receiving counseling at the hospital, which helped ease their concerns. Their fears were further alleviated after visiting Dr. Jayanth's hospital and seeing other patients who looked normal post-surgery.

Janani's parents are in a consanguineous marriage. Vanivilas Hospital has a strong surgical team that performs such procedures on a co-payment basis, charging between Rs 4,000 and Rs 8,000 per surgery. However, the waiting list is extensive, often requiring 8 to 10 months to secure a surgical slot, which can hinder optimal recovery. This delay is why many patients are referred to Dr. Jayanth.

Janani's mother is a homemaker, and her father works as a welder. Affording the treatment would have been difficult, making the free surgeries a significant relief for them. The surgeries have had a profound impact, particularly in resolving feeding difficulties and aiding weight gain. Despite receiving nutritional supplements, maintaining adequate weight remains a challenge.

Throughout the process, doctors have been readily available for consultations, ensuring that all minor health concerns were addressed. Janani initially attended speech therapy sessions regularly but now only requires follow-ups every three months. Additionally, she benefits from online therapy sessions and has completed 78 speech offline therapy sessions so far.

4) Sayida Fatima

Sayida, the only daughter of her parents from Bengaluru, is now two and a half years old. Her mother was unaware of her cleft palate until birth but was informed about the availability of free surgeries. When Sayida was three months old, she was taken to Dr. Jayanth, who reassured the family that surgery was possible. However, some relatives

and friends instilled fear by suggesting the procedure might be life-threatening, causing the mother to delay treatment. Eventually, after seeing another child who had undergone surgery and improved significantly, her fears eased, and she brought Sayida to the hospital.

Sayida has undergone one surgery, which successfully stopped food from escaping through her nose. Before the procedure, her mother struggled to feed her—even in an upright position, food would sometimes come out of her nose. Now, she can be fed in any position, and she comfortably consumes soft foods. She continues to attend regular check-ups and speech therapy.

Born with only a cleft palate and not a cleft lip, her next procedure will be determined based on how she progresses after palate surgery. By the age of nine, she may require additional corrective procedures. As children grow, therapy sessions become more frequent. Since cleft palate can sometimes lead to hearing issues, her condition will be closely monitored.

Sayida's father works in his grandfather's garage, and her family is grateful for the free medical support that has helped their daughter receive the necessary care.

5) Kirtan Jasveer

Kirtan, now 2.2 years old, underwent his first surgery at six months old. His mother had delayed getting a scan, so she was unaware of the cleft until birth. At delivery, she was informed that surgery could correct the condition and was referred to Dr. Jayanth.

She brought Kirtan to him when he was two months old and continued to attend regular follow-ups. Doctors advised that surgery could be performed once the baby reached a weight of 5 kg. After the procedure, the most noticeable improvement was that Kirtan could drink milk properly.

Kirtan's mother holds a Bachelor of Commerce degree and works in an office, while his father, who dropped out of school in the seventh grade, works in a stone quarry.

Financial constraints would have made affording the treatment extremely difficult for them. Additionally, the parents are cousins, highlighting a genetic factor in the condition.

6) Ahmed Zilan

Ahmed, now 18 months old, underwent surgery at the age of three months. His parents learned about his cleft condition during a prenatal scan in the seventh month of pregnancy. When he was born, the doctor provided a referral letter for Dr. Jayanth and advised them to seek treatment there.

Due to his condition, Ahmed was unable to drink milk from a regular bottle or breastfeed. Instead, his parents fed him using a special bottle designed for babies with cleft conditions. He frequently suffered from colds, as food would escape from his mouth while eating. However, after the surgery, these difficulties disappeared, greatly improving his well-being.

Ahmed's father, a carpenter, dropped out of school in the third standard. His mother attended a Madrasa and has studied only the Quran. They diligently follow up on check-ups and adhere to their doctor's recommendations. His father expressed that, had the surgery not been free, he would have found a way to raise the money to ensure Ahmed received the necessary treatment.

Ahmed also has an older brother, who is five years old and in good health.

7) Charvik C

Charvik, now three and a half years old, was referred to Rangadore Memorial Hospital by the facility where his mother had given birth. When he was just three months old, she brought him to Dr. Jayanth, and he underwent surgery at nine months.

During infancy, Charvik frequently suffered from colds, fevers, and recurring infections. His palate surgery was completed a month ago, addressing many of these issues.

His mother has completed her education up to the tenth grade, while his father, a farmer, dropped out of school early. Initially, they had considered terminating the pregnancy. However, after learning at the hospital that treatment would be provided free of cost, they decided to continue with it.

The parents are in a consanguineous marriage and are now aware that it has contributed to their son's condition. They remain committed to ensuring Charvik receives the medical care he needs.

8) Jeevan

One-year-old Jeevan underwent surgery at three months old to correct both his cleft lip and palate. His first procedure addressed the lip, and he recently had another surgery for his palate. His parents first learned about his condition during a prenatal scan in the seventh month of pregnancy. Initially, they considered terminating the pregnancy, but the doctor advised against it, as it was too late for such a decision.

Jeevan was delivered at Vanivilas Hospital, where his parents were referred to a specialized treatment center. As both work in a garment factory, they have left Jeevan, their only child, in the care of his grandmother, as they are unable to look after him themselves. His father has completed an ITI course, while his mother holds a degree.

Due to their circumstances, Jeevan is being raised by his grandmother while his parents live in another town. Earlier, he faced difficulties with feeding, but following the surgery, he has improved significantly. Although still very young, he has begun speaking a few words. His parents expressed that, had the surgery not been free, they would have found a way to raise the necessary funds to ensure his treatment.

9) Mohit Shriya

Four-month-old Mohit has a seven-year-old sister. His mother learned about his cleft condition during a prenatal scan. Although termination was considered, medical professionals provided counseling and assured them that surgical procedures could

correct the condition. Since Mohit was born with only a cleft lip and not a cleft palate, he did not experience feeding difficulties or related health complications. His father left school after the 10th grade, while his mother holds a degree. The father works as a sales executive in a shop. Had the surgery not been available at no cost, the parents expressed that they would have found a way to raise the necessary funds for the procedure.

10) Arsia Khanum

Arsia, now four years old, was diagnosed with a cleft condition after birth. Her parents had initially taken her to a doctor due to a fever, and during the examination, the doctor noticed her cleft and referred them to Rangadore Memorial Hospital and Dr. Jayanth for treatment.

Born with both a cleft lip and palate, Arsia was taken to the hospital when she was just a month old. There, her parents were informed that surgery would be performed when she reached six months of age. She has an older sister and a younger brother, both of whom do not have any medical conditions.

Her father, who dropped out of school in the sixth standard, works as a mechanic. The family was aware that the treatment would be free. Although they were approached by another hospital for care, they chose Rangadore Memorial Hospital for her treatment. They are originally from Tumkur.

After undergoing surgery, Arsia's father believes she looks much better and has seen remarkable improvement in her ability to speak, thanks to early intervention. Further procedures and speech therapy will be required to enhance her communication skills.

11) Kirtana K

Sixteen-year-old Kirtana has undergone a total of six surgeries for her condition. The first five were performed at a different hospital, where she was satisfied with the care she received. Her treatment there was also free of charge. However, for her most recent procedure, she was referred to Rangadore Memorial Hospital.

There was no specific reason for the switch—she had no complaints about her earlier hospital. She came to RMH because it was recommended by Vanivilas Hospital staff.

Kirtana's journey has involved multiple surgeries at various stages, each playing a crucial role in improving her condition. Despite the challenges, she and her family have remained committed to her treatment, seeking out the best care available. Her experience reflects the importance of accessible medical interventions and the role that different hospitals play in ensuring continuity of care. She will continue with her studies.

12) Khatija

Eighteen-year-old Khatija was referred to Rangadore Memorial Hospital by Vanivilas Hospital. So far, she has undergone six surgeries at RMH and is very pleased with the treatment she has received. Although she did not pass her exam, she is now actively searching for a job and looking forward to new opportunities. She is doing a computer course. Despite the challenges she has faced, she remains determined and hopeful about her future.

13) Nisarga R

Nisarga, now 11 years old, does not recall the exact timing of her surgeries but knows that she was born with both a cleft lip and palate. She is currently in the 6th standard and is free from any health issues, leading a normal and healthy life.

Hyderabad:

1) Kamal Ashwin

Kamal, now two and a half years old, was diagnosed with a cleft condition during an ultrasound in the eighth month of pregnancy. Her gynecologist informed the parents about the condition but reassured them that it could be corrected with surgery**.**

Kamal's father works as a government employee in Andhra Pradesh, and his brother is a dentist. Her mother, a postgraduate, previously held a job but has since left work to

focus on her child's care. Kamal also has an older brother who does not have any health issues.

Although Kamal has started speaking a few words, she requires speech therapy. There is some concern that she may be borderline mentally challenged, but the parents have not consulted any other doctors regarding developmental milestones.

The family was informed that the treatment would be free, but they **are** uncertain about the organization funding the expenses. Kamal has successfully undergone lip and palate surgeries and can now eat all types of food without difficulty.

Her parents are extremely satisfied with the care and services provided by the Centre and wholeheartedly recommend it to any child with a cleft condition they may come across.

2) Arhan

Arhan, a nine-year-old student in the fourth standard, has undergone three surgeries—lip repair, palate correction, and most recently, bone grafting. His mother took an active role in his recovery by learning speech therapy techniques, which she practiced at home to support his progress. As a result, both his appearance and speech have improved significantly.

Arhan has an older sister who is in good health. His mother learned about his condition during a prenatal scan in the fifth month of pregnancy and was informed that surgical treatment was available. She first brought Arhan for a checkup when he was three months old, but due to his extreme weakness, he was sent back for further monitoring. He also suffered from frequent bouts of fever and pneumonia, which further delayed intervention.

Children with cleft palate often struggle with proper intake, making weight gain difficult. Arhan's condition followed a similar pattern, and his surgery was finally performed when he was 18 months old.

His father works as an auto-rickshaw driver, and the family would have faced significant financial challenges in affording the treatment. Thankfully, they were able to access the necessary care, ensuring Arhan could receive the medical attention he needed.

3) Mohika

Two-and-a-half-year-old Mohika has undergone two surgeries so far. Her parents learned about her cleft condition during a prenatal scan in the sixth month of pregnancy. Having never seen a baby with a cleft lip before, they experienced shock, distress, and anxiety about how to care for her.

Feeding was a major challenge during the first three to four months until they figured out the best method to nourish her. The family resides in Adilabad, approximately 400 km from Hyderabad. Both parents are graduates, and the father works as a tailor, with the mother assisting him in his work.

Mohika has a younger sister, whom her mother recently delivered and is still recovering in the hospital. Her father is deeply grateful for the financial support provided by Persistent, which made her treatment possible. He believes the most significant change after the surgery is that she now looks healthy and well.

4) Adam

Nine-year-old Adam attends a regular school. His mother noticed his cleft lip at birth but was unaware of the cleft palate until the doctor examined him. She was advised to take him to Dr. Vijay Kumar in Hyderabad for treatment.

The initial months were challenging, as Adam struggled with feeding and cried constantly due to hunger. His mother had difficulty finding a suitable way to nourish him until he was around three to four months old. He has an older brother who is healthy. While his parents are related, the mother mentioned that their relation is not very close.

His first surgery was performed when he was about a year old, followed by palate correction and bone grafting more recently. These procedures have made a significant difference—his speech has improved, he can drink liquids without them leaking from his nose, and his appearance has also changed for the better. Additionally, he has gained weight.

His mother has been actively supporting his recovery by practicing speech therapy techniques at home. Although his teacher sometimes struggles to understand him, his speech is gradually improving. His father works as a journalist, and the mother home maker. She is extremely grateful for the treatment and support provided by the Centre. While they would have found a way to raise money if necessary, they are relieved that the surgeries were provided free of charge.

5) Sandhya

Sandhya's family resides in Kurnool, approximately 200 km from Hyderabad. When they visited a government hospital, the doctor informed them about her cleft condition but reassured them that it could be corrected through surgery in Hyderabad.

She is the youngest of four siblings, with three older sisters. Her father, a laborer, and her mother are both illiterate. Fortunately, they were aware that the surgeries would be provided free of cost.

So far, Sandhya has undergone two surgeries, with her father taking her to Hyderabad each time. She can say a few words, but her speech remains limited. At seven years old, she appears smaller than typical for her age. One more surgery is planned, as cleft lip and palate treatment usually requires five procedures in total.

With only her father as the sole earning member of the family, affording the treatment independently would have been extremely challenging. He is deeply grateful for the care and support provided by the hospital, which has helped his daughter receive the necessary medical attention.

6) Jayashri

When Jayashri was six months old, her parents discovered that she had a cleft palate. She has two brothers—one older and one younger—both of whom are healthy. Since she does not have a cleft lip, her appearance remains unaffected. Depending on how her speech develops, she may require an additional surgery in the future.

Her family is from Anantpur district, a considerable distance from Hyderabad. When they initially sought medical advice at a hospital in Anantpur, they were referred to Hyderabad for further consultation. Her father works as a construction laborer on daily wages, making it difficult for the family to afford the surgeries had they not been provided free of cost.

AVR Hospital, which is affiliated with ABMSS, has a partnership with Anantpur. Patients from the district generally have two options for treatment—traveling to either Bengaluru or Hyderabad. Although Bengaluru is geographically closer, many prefer Hyderabad because it is a Telugu-speaking region, allowing them to communicate more comfortably without language barriers.

7) Sathu

Sathu, now four years old, has undergone three surgeries. His first two procedures addressed his bilateral cleft lip during his first year, followed by a palate surgery in 2023. His parents were aware of his condition before birth but chose to accept it as part of their faith.

He has a younger brother who is in good health. Feeding was particularly challenging due to his bilateral cleft and palate issues, with food frequently escaping through his nose. However, after surgery, these difficulties have completely resolved, and he can now eat properly. His father sees this as the most significant change, apart from the noticeable improvement in his appearance.

Sathu's father, a construction worker with no formal education, has not enrolled him in school yet but now plans to do so. Given his financial circumstances, raising money for the surgeries would have been extremely difficult, and he is grateful that the treatment was available free of charge.

8) Group Interview

Among the children in the group, two were borderline cases of Down syndrome. In most instances, their parents were informed about the condition during prenatal scans. However, since they were assured that surgical intervention was available and provided free of cost, they chose to continue with the pregnancy.

All these families come from economically disadvantaged backgrounds, many classified as Below Poverty Line (BPL). Raising funds for treatment would have been extremely difficult for them, with some traveling as far as 500 km overnight to reach the hospital. The high patient turnout for interviews highlights the strong bond between the coordinator and the families. The program coordinator maintains regular contact with patient families, offering support and answering their questions whenever needed. Parents express great satisfaction not only with the medical treatment but also with the compassionate communication from the staff and doctors.

One of the children, a young boy, underwent palate surgery at the age of six, significantly delaying his speech development. Frequent illnesses prevented earlier surgery. His tongue was attached to his lower jaw, a condition requiring surgical separation, which could be performed along with palate correction. This issue often goes unnoticed until children begin speaking, as limited tongue movement affects speech. When palate surgery is performed late, speech therapy becomes essential for language development.

Most parents learned about the condition during pregnancy, but since the diagnosis often occurred in the third trimester or late second trimester, termination was no longer an option. Doctors consistently reassured them that surgical solutions were available.

One of the fathers, a graduate, discovered his daughter's cleft condition immediately after birth. However, at four years old, she exhibits low IQ and may require enrollment in a special school, as she can only speak a few words.

Another mother has three older daughters, with her youngest child being an unexpected pregnancy at the age of 45—kept in hopes of having a son. The child, who has both cleft lip and palate, is unable to sit even at the age of three. Dr. Vijay emphasized that she requires further screening for medical or neurological conditions. Her father, a farmer, has struggled with ensuring her proper care.

One of the families has two children affected by both cleft lip and palate, along with Down syndrome. Additionally, one of the daughters also suffers from hearing impairment, further complicating her developmental challenges.

Dr. Vijay's tie-up with RBSK ensures that all government hospital cases are referred to him. As soon as a child is born with a cleft condition, parents are directed to his care, enabling early intervention and treatment. This system guarantees that no patients are overlooked, as all those referred come from government hospital categories.

Many of the families affected are marginal farmers or agricultural laborers. Some own small plots of land while others work on neighboring farms, relying on daily wages for survival. Some have small businesses such as kirana shop, tailoring shop, etc.

If the child has only unilateral cleft lip, one surgery is all that is needed. For bilateral cleft lip two surgeries may be required. If the child has cleft palate as well, five surgeries are done at different stages which increases the treatment cost considerably. These children also need speech therapy. The treatment for cleft lip and palate may continue till the child is 15 years of age.

Sometimes the treatments are delayed due to low awareness of the parents on the procedure of the treatment, logistic difficulties, loss of income for daily wage labourers. Other reasons are low weight of the baby, other infections and low HB.