

cleft xchange

OFFICIAL CLAPAS FSG NEWSLETTER



April – August 2005

In This Issue

2. NKF Children's Medical Fund Subsidises Treatment for 6 More Cleft Patients

3. CMF Opens Southeast Asia's First Cleft and Craniofacial Centre

4. Cleft Management

6. Patient's Story – A New Chapter in a Father's Life

8. CMF Activities

Chairman's Message



Dear fellow FSG members,

The CLAPAS Family Support Group (FSG) is now in its 2nd year of partnership, which began in May 2004, with the NKF Children's Medical Fund (CMF). On behalf of the committee, I am happy to report that the FSG has steadily progressed and consolidated its activities. Notable amongst these are the tri-annual newsletters and bi-annual talks. Copies of our newsletters have been distributed to public and private hospitals, reaching the majority of gynaecologists, paediatricians and plastic surgeons in Singapore.

The talks and newsletters have also resulted in a considerable increase in the number of calls from parents of newborn babies with cleft lip and palate, as well as from those who detected craniofacial deformities in their unborn children through ultrasound scans.

Between 1 April and 30 June 2005, 11 new applications for financial assistance have already been reviewed by the committee compared to 18 cases for the whole of last year. At this rate, the FSG expects a quantum jump in applications this year over the previous year. This statistic shows that our outreach programme is creating significant public awareness. The committee welcomes and expresses its thanks to its new coordinator, Tracia Neo, for her excellent work.

However, since all our cases so far have been from SGH and KKH, we will double our efforts over the coming months to reach out to other public hospitals in the country. We will not rest on our laurels for there remains much more to be done. Help us to spread the message around.

Happy reading!

Yours sincerely,

Richard Cheng



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CLAPAS FSG is now online!

Visit us at www.clapasfsg.org.sg to know more about our activities. If you have a story to contribute, feel free to e-mail it to clapasfsg@gmail.com.

Need counselling or help with your child with cleft lip and palate? Want to know how you can help? Contact Ms Tracia Neo at 63515 424 or e-mail her at tracia.neo@nkfs.org.



Cleft Management



First Stage of Cleft Management

In the previous issue (January to April 2005) of Cleft Exchange, I outlined the overall treatment plan for babies or children with cleft lip and palate right after birth until they are 18-years-old. In this issue, I will explain in greater detail the first stage in the treatment plan, i.e. in babies from the time of birth until they are three or four months old.

One of the goals in cleft management has always been to reduce the number of steps or stages involved in the treatment plan and to improve the result of each stage of treatment. Nasoalveolar Moulding (NAM) and gingivo-periosteoplasty (GPP) are two techniques that have achieved such goals. NAM and GPP are recent advances in the treatment of cleft babies that have not only reduced the number of operations in cleft children as they grow up, but have also improved the cosmetic result in children who underwent the treatments at a very young age. (Figure 1)

The first stage of cleft management involves:

- a) Pre-surgical Orthodontics - NAM (starting at birth)
- b) "3-in-1" Surgery - repair of cleft lip, nostril and GPP (at three to four months old)

What is NAM or Nasoalveolar Moulding?

NAM is a technique developed by Dr Barry Grayson (cleft orthodontist) and Dr Court Cutting (cleft surgeon) at New York University, USA. It is an improvement on the other techniques that have been used in the US and in Europe for decades.

NAM is a non-surgical method of reshaping the gum, lip and nostril before the baby has his first cleft repair surgery over a period of three to four months. This technique will lessen the severity of the cleft even before the first surgery is done. Following this treatment, patients are then suitable for the "3-in-1" surgery including GPP – which would otherwise not be possible – when the infant is between three and four months old.

When should NAM begin and what does it involve?

NAM begins before the first surgery, with parents working with the cleft orthodontist, when the child is about a week-old (Figure 1a).

Within the first couple of weeks after birth, the cleft baby is fitted with a custom-made moulding plate that looks like a feeding plate or denture plate (Figure 1b). The device is attached using a small rubber band that is taped to the baby's face (Figure 1c).



Fig 1a: A child born with unilateral cleft lip & palate. The nose is collapsed, lips & gums are widely separated.



Fig 1b: Moulding plate and nasal stent use in NAM.



Fig 1c: Moulding plate in place.

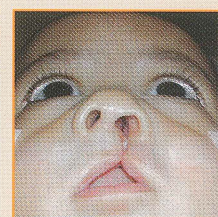


Fig 1d: Collapsed nostril lifted, lips & gums touching.

The moulding plate causes no pain and after the first few days the plate usually does not bother the baby at all and is accepted as part of his face.

Unlike some older techniques, the moulding plate does not push or stretch the delicate tissues. Instead, it helps gently direct the growth of the gums. The baby wears the moulding plate 24 hours a day, seven days a week. The tape is changed and the moulding plate cleaned everyday or as often as needed.

After the baby has worn the moulding plate for a week, the orthodontist slowly adjusts the shape of the plate. Each adjustment is very small, but effectively guides the baby's gums as he grows.

Adjustment of the moulding plate is done by the orthodontist weekly or fortnightly, depending on the progress.



Once the gap in the gums is small enough, a special wire with a soft, round tip is then attached to the moulding plate and is directed into the deformed nostril on the side of the cleft lip. This wire is then slowly adjusted to lift up the nose, opening the nostril by gradually moulding the deformed cartilage.

By the time of the surgery, the nostril would be lifted and narrowed, the gap in the gums would be reduced and the separated upper lip would be closer together.

What is the "3-in-1" surgery?



Fig 1e: Moulding plate and nasal stent use in NAM.

After the NAM treatment, the baby then undergoes surgery at about three to four months old to repair the cleft lip and nostril. In most cases, GPP can then be performed at the same time to completely close the cleft in the gum. This is usually only possible after the patient has undergone NAM treatment (Figure 1e).

Performing a GPP at the time of the lip and nostril surgery can eliminate the need for a future alveolar bone graft (an operation usually carried out between the ages of seven and 12 years) in approximately half of the child patients (Figure 2a, 2b).

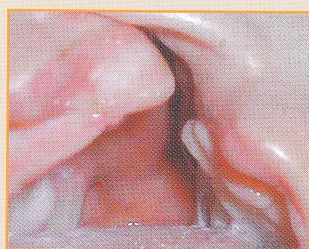


Fig 2a: Before NAM - the gums are widely separated.

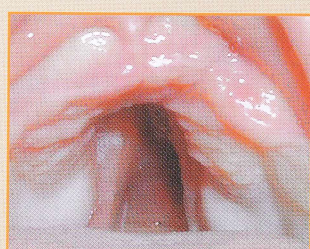


Fig 2b: After NAM and GPP (before palate repair) - cleft in gums completely closed.

What are the advantages of NAM?

NAM repositions the cleft segments, hence reducing the severity of the deformities. With NAM, the cleft orthodontist can improve and narrow a large cleft in the months before the child's first surgery. A smaller gap to repair means that the surgeon will have to apply less tension when he closes the cleft, resulting in a better cosmetic outcome. A better result from the first surgery would also mean fewer surgeries required later in

childhood. In our experience, treatments using NAM produce a better result in the end (Figure 3a, 3b). This is especially true in children with bilateral cleft lip where the gaps are even bigger.

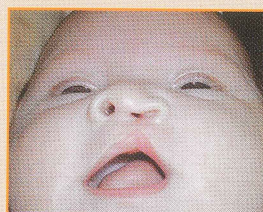


Fig 3a: Children treated without NAM

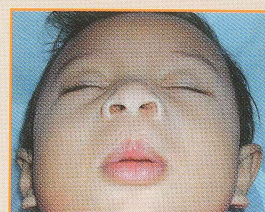
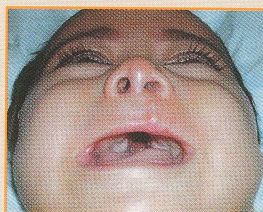


Fig 3b: Children treated with NAM after surgery

In the past, surgery on the lips, nose and gums were done separately in multiple stages between birth and the age of 18. Now, with NAM, the surgeon is able to combine three separate surgeries into one - repairing lips, nose and gums (by GPP) all at the same time. This not only lessens the psychological trauma experienced by the child but also reduces the financial costs of the entire treatment (Figure 4a, 4b, 4c).

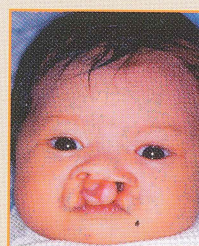


Fig 4a: Before treatment at birth.



Fig 4b: After treatment (9 months old) - with NAM and surgery.



Fig 4c: Child at 4 years of age.

Special thanks to Dr. Catherine Lee (Camden Medical Centre), Director of the Singapore International Cleft-Craniofacial Team for contributing this article. Do not miss the next issue of her article on Cleft Orthodontics Management: Alveolar bone Grafting and Interceptive Orthodontics!

For more information, please contact the team's coordinator, Ms. Tracia Neo at 68360554 or e-mail her at tracia.neo@siccc.com.



A New Chapter in a Father's Life



I am Winston Lee and I am currently serving as a committee member of the CLAPAS FSG. My wife, Elsie, has bilateral cleft lip and palate and we have a 10-years-old daughter. Like Elsie, my daughter Joan was also born with cleft lip and palate.

When my wife was four months pregnant, her gynaecologist discovered that our baby had a cleft lip through an ultrasound scan. My wife and I were stunned and did not know how to react to the news. We did not expect this to happen to our baby as we were not aware that, as a cleft lip parent, Elsie had a higher chance of having a child with a similar birth defect.

The gynaecologist asked us if we would like to do some tests to check if our baby had any other abnormalities. The test results showed that our baby was fine. The gynaecologist then informed us that we had the option to keep or abort the baby.

On our way home that very day, my wife and I were very quiet. We did not talk much as we were both thinking about the options the gynaecologist had offered us. I was worried that others would tease my daughter as she grew up and I was also concerned about the medical bills. Despite all these, I told my wife to keep the baby as I believed that she was a gift from God. I promised Elsie that we would be able to cope with all the challenges hand-in-hand.

On 1 February 1995, Joan was born. I was pacing nervously in the delivery room at the Singapore General Hospital. I did not know how Joan would look like. I was both anxious and worried. Finally, the nurse brought Joan to me. There was a slit dividing her upper lip into two. I thought to myself that this was probably how Elsie looked like when she was born. I felt more determined to provide both of them with a better life.

The next day, we took Joan to Ward 63 for a plastic surgery. A very friendly nurse greeted us and showed us around the ward, where we saw many cleft lip and palate patients. There were babies, children and teenagers of various races. Sister Lee explained to us the numerous surgeries that Joan would have to go through during different stages of her life. Apart from that, she also mentioned that Joan would need to attend regular sessions with a speech therapist and an orthodontist. Elsie and I felt re-assured as we knew what to expect in the course of Joan's treatment. We also saw how well the staff took care of the patients. We both felt that Joan was very fortunate to be born at a time when medical treatments for cleft lip and palate patients are technologically advanced. When Elsie was a child, treatment was not as sophisticated and affordable.

Before we left the ward, Sister Lee informed us about the CLAPAS family support group. As most of the members of the family support group were parents of young patients, it was easier for us to relate to them and garner motivation and support.

We were given an appointment to see Professor Lee one month later. On 8 March 1995, I met the soft-spoken Professor Lee and Nurse Foo for the first time. Professor Lee was a man of few words. He did not talk much. He only told us that Joan would be scheduled for her first surgery when she was three-months-old.

Joan has undergone several surgeries since then. Elsie and I have taken turns in bringing Joan for her speech therapy and orthodontics treatment. Although it has been quite taxing for us, we both feel that it is all worth our while. We are thankful for the assistance and genuine care that the CLAPAS family support group, Professor Lee, Sister Lee and all the staff of Ward 63 have shown us. Without them, I do not think that Elsie and I would have been able to cope this well.

Last but not the least, I would like to tell other parents that having a child with cleft malformation does not mean the end of the world. You should not feel lost as help is out there. For me, having Joan was the beginning of a new chapter in my life where new friendships have been formed. All the love and support of my family and friends have definitely made the journey easier and more enjoyable.

Winston

If you want to share your story about how the FSG has helped you and your family, please e-mail us at clapasfsg@gmail.com.



给女儿一个完整的笑容

我 叫李来安，和很多父亲一样，我希望有一个幸福的家庭，女儿能时时绽开美丽的笑容。然而，这一切对我却来之不易。

我的妻子陈招虹有唇腭裂，她怀孕4个月时，超声波检查发现胎儿有唇腭裂。一听到这个消息，我们都惊呆了。没想到妻子的唇腭裂遗传给了女儿。虽然胎儿其他方面都很正常，医生还是建议我们慎重考虑是否要生下这个孩子。那天回家的路上，我和妻子都沉默不语，内心苦苦挣扎着。我担心无法支付昂贵的整形费用，更担心孩子长大后受别人嘲笑，但是我又不想失去这个孩子，我相信她是上帝的礼物。想到这里，强烈的父爱牢牢占据了我的心，我顾不得种种担心，决定将孩子留下来。我对妻子说，我一定会做个好父亲，将来无论情况多糟，我都会和她共同面对。

1995年2月1日，我们的女儿佳恩在新加坡中央医院出世了。在产房外等待时，我的心犹如热锅上的蚂蚁，焦急不安，不知道我的女儿究竟会长得什么样。终于，护士把女儿抱出来了，我一眼就看到她裂成两瓣的上唇，那么醒目。

但是，从护士手里接过女儿的一刹那，我的心就被融化了。她小小软软的身体蜷缩在我怀里，那么需要保护，虽然她不够完美，但是我一样要给她幸福的人生。我和妻子决定竭尽所能为女儿治病，让她的笑容不再残缺。

女儿出生的第二天，我们就带她前去医院整形科进行咨询。医生说，佳恩在生长发育阶段需要分几次接受整形手术，并进行语音治疗和牙齿矫正。第一次整形手术将在她满3个月的时候进行。

虽然治疗过程会很漫长艰难，但是咨询过后，我们看到了希望。在整形科，许多不同种族、不同年龄段的唇腭裂孩子都在接受治疗，而他们的父母则成立了家庭互助小组给孩子们打气，也互相帮助。看到孩子们在医生精湛的医术下，变得完美的笑容；在护士细致的照料下，快乐的身影，我和招虹信心倍增，心里感到踏实多了。我们很庆幸女儿出生在现在这个时代，先进的医术再加上家庭互助小组的帮助，她一定能活出一个新的人

生。而这在我妻子小时候几乎是不可能的，也负担不起。

这些年来，佳恩已经接受了好几次面部整形手术、语音治疗和牙齿矫正。虽然我们耗费了大量精力和金钱，但这一切都是值得的。我不后悔将佳恩带到这个世上，她让我尝到了为人父亲的幸福，翻开了我人生新的一页。这全都要感谢家庭互助小组的朋友和整形科所有医护人员。在漫长痛苦的治疗过程中，是他们一直关心帮助我们，陪伴我们渡过一个又一个难关，我们一家才能有今天的幸福生活。

现在，我也成为这个家庭互助小组中的一员。我要告诉所有唇腭裂孩子的父母：千万不要绝望，也不要放弃，我们一定会支持你们。大家携手努力，就能给孩子们一个完整的笑容，还他们一个圆满的人生。

诚祝安康！

李来安

如果您愿意和大家分享有关家庭互助小组的故事，请电邮至 clapasfsg@gmail.com



李来安和妻子陈招虹，
女儿李佳恩绽开快乐笑容