



**Associazione Ti Racconto un Sorriso**

**[www.tiraccontounorriso.it](http://www.tiraccontounorriso.it) -**

**[info@tiraccontounorriso.it](mailto:info@tiraccontounorriso.it)**

## **CLEFT LIP AND PALATE - A PRACTICAL GUIDE**

Tips for parents by parents as a guide for the Smile House path

Edited by

**Ti Racconto un Sorriso**





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### **BEFORE BIRTH OR ADOPTION**

#### **What is a cleft lip ?**

The Cleft lip in itself is a correctable widespread formation failure that does not affect in any way the everyday social, educational and sports life of the child!

It's a congenital malformation due to an anomaly in the growth; it is a slit and can be defined as cleft lip (LS) when it only includes the lip, cleft palate (SP) when it comprises the palate and cleft lip and palate (LPS) when it includes the lip, gum and palate both soft and hard; sometimes it may be associated with other diseases and syndromes such as the Pierre Robin.

#### **Knowing the reference center**

When by way of ultrasound exploration a diagnosis of facial cleft is made, or in case of adoption, should you be matched to a child with this pathology, it is important to decide where to have your son/daughter be taken care of, or even where to give birth even though gestation and birth do not differ from those who have children without the disease.

We recommend that you make an appointment with the persons in charge of the specialized centers, even those outside your region, to have an idea of how they are organized and take better decisions for your needs.

In Lombardy, the center of reference is the department of maxillofacial of the San Paolo Hospital of Milan, in combination with a Smile House, a unit that includes multidisciplinary Surgeons, Orthodontists, Speech Therapists, Otorhinolaryngologists, Psychologists, Pediatricians and Geneticists.

The center is located at the San Paolo, Block B - 9th floor; meetings are held on Monday morning with the presence of the coordinator of the Smile House and the psychologist and can be accessed freely by email to [segreteria@smilehouse@ao-sanpaolo.it](mailto:segreteria@smilehouse@ao-sanpaolo.it)



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The secretariat is located in the second room on the left; at this stage feel free to express all your doubts and curiosity; you may ask to visit both the Smile House and the hospital and even exchange a few words with the parents in the waiting room, to better understand the whole process.

**Once everything is clear to you, waiting for the arrival of the little one will be more serene!**

### Knowing the medical and paramedical team

The medical team of the Smile House is composed of:

- Surgeons:** are the doctors who operate the children, their job is to close the cleft or correct the results of previous operations. When you talk to them have them clarify all aspects of operations and post-operative; you will meet them at the follow up visits, before and during hospitalization for the operations.
- Orthodontists:** are the doctors who deal with the management of the plate, take care of the teeth, especially for orthopedic and orthodontic treatments. You will be in contact with them early in your path if you will be prescribed the plate and usually after that the baby will have definitive teeth.
- Speech Therapists:** dealing with communicative- linguistic development of the child; speech therapy sessions, if necessary, begin between 3-4 years of age; in the case of adopted children they will assess individually the means of intervention.
- Otolaryngologists:** are the doctors who care to treat disorders of the ears of our children, and you can always ask for a consultation.
- Psychologists:** are concerned with assessing the psychological aspects in children but also adolescents; you will meet them at the time of first visit, but if you need them you may require a consultation at any time.



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- Pediatricians:** dealing in general the health of our children; you will see them at the pre-admission visit
- Geneticists:** they study the genetic component of the pathology e it's inheritability; for a consultation you may apply at the secretariat of the Smile House
- Head nurse:** manage the deparment and also the waiting list for admission and pre- admission

## AFTER BIRTH OR ARRIVAL

### Early hours and lactation

Children who are born with cleft lip and palate, can have problems feeding in the first few months until the closure of the palate. Every mother finds the best way for her child: some children were fed with normal bottles, maybe widening a bit the little hole to help the coming out of the milk; in other cases special bottles are used such as the “Medela Special Needs” or the Habermann bottle which has a long and soft teat with a small milk reservoir to help push the milk into the mouth of the child and a valve reducing swallowed air. Or you can use the Nuby bootle, the Softflex Silicone Nurser one has a soft bottle that you can squeeze to help the child: those who used it from birth employed a medium flow teat. You really have to keep in mind that these children have a normal deglutition as any others, and if sometime, the food coming off from the nose don't be worried it's normal: **often the best method is to have a lot of patience.**

### Law 104 and disability

Parents, including those of adopted children, with children suffering from cleft lip and palate, can avail themselves of the benefits of the law 104/92, which may comprise: an extension of parental leave, 3 days a month of paid leave, or



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alternatively 2 hours per day of paid leave and other tax relief on expenses incurred. So after the birth or the arrival of the child in Italy, it is advisable to apply for access to these facilities: first consult your pediatrician (or family doctor authorized to make online applications) who will file the application stating the pathology of the child and will issue a registration number. Then with that number go to a patronage handling these matters and wait for the notice, by registered mail, to undergo a visit in your ASL district. After the visit, given the sometimes very long time to get the final report, it is advisable to ask for a temporary certificate to take advantage right away of the special leave or alternatively the 3 days per month.

An application for disability insurance can also be made, i.e. a small monthly contribution to support families of disabled children who have to bear expenses related to attendance at a school, public or private, or a specialized center for treatment or rehabilitation. Don't be scared about the word "disability", **children with LPS are not disable**, in fact the acceptance of applications for disability and 104 law are not certain, but they are tied to the discretion of the medical committee that will evaluate your case, and, moreover, especially after they've been operated the certificate could be revoked due to the end of "disability".

### First visit to the Smile House

You may book it through the department of obstetrics where the child was born or by calling the CUP 800.638638 asking for a maxillofacial visit at the Smile House, reporting the diagnosis. During the first visit, if necessary, an imprint of the orthodontic plate will be taken and delivered after a few days. Be patient, waits can be long because there are always many children to visit, so plan for the food, diapers, and spare clothes.



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### The orthodontic plate

The protocol adopted in some instances by the team of San Paolo provides for the use of neonatal orthopedic plates with the aim of facilitating feeding and to control the development of the jaw. In cases of bilateral cleft lip and palate a particular one is used which also helps to change the shape of the nose. The plates are checked and modified during the growth by the team of orthodontists and are kept in place with traditional denture pastes. Beware that they can be modified at each visit, so not only remember to bring everything you need to have it put it back, but always check that the baby is well and eats in the proper way. Stay a little longer in the Smile House to verify that everything is fine. Adopted children are usually a bit older and do not need plates

### Days of visit

The days of visits usually are on Mondays and Thursdays, and you have to be at the hospital department with the doctor's prescription. If the booking has been made directly at the hospital, you do not need to register and you need only to deliver the prescription to the personnel of second door at your right at the Smile House. Should you have booked through the toll free CUP number you need to go at the first floor and register there. Do not forget the medical records of the child that can always be useful.

So wait very patiently your turn in the waiting room (first door on the right). Some Smile House volunteers will keep the kids busy with games and drawings. Take this opportunity to exchange views with the other parents, and you can do it also later on during recovery. As mentioned above waiting can be long because there are always many children to visit, so plan for the food and change of clothes. If you need to check the plate, you have to take with you everything you need to put it back. At the end of the visit you will be given the prescription for the next visit and the medical report. **Remember always to book the visit:** you can do so through the CUP 800638638 toll free number or directly at the hospital at the counters on level -1 letter E.



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### **Pre -admission**

The pre-admission, day-care mode, is the day in which tests and examinations are carried out in view of the operation. You will be contacted by telephone by the head nurse who will give you the instructions. It 's time to clear up any doubts then feel free to ask any question. We suggest to take note of the things to ask. Normally the child is required fasting 4 hours for liquid food and 8 hours for solid food before the pre-admission. In addition to a pediatric visit to verify the medical history and the health status of the child, blood tests, electrocardiogram, and, if appropriate, allergy tests and specialist visits are carried out. You will be interviewed by the surgeons and the anesthesiologists for clarification on the intervention, and you will be asked to sign the consent for surgery. In the case of adopted children these tests can be carried out at the time of the screening tests after the adoption. All visits take place in the department of pediatrics at the 7th floor of the block A.

From the date of the pre-admission usually it takes not less than 3 months for the surgery, but sometimes could be longer. In some instance they ask to parents to have a blood test for genetics examinations.

## **THE OPERATION**

### **The department**

The maxillofacial department is located on the Block B - 8th floor. Rooms used to accommodate young patients are number 6 and number 8. They are equipped with beds for the children, as well as tables and chairs, cabinets and small sinks. The mini-kitchen is positioned in front of the two rooms and is equipped with a table and chairs, high chairs, a microwave, a refrigerator with freezer to store food and drinks and a sterilizer. The hospital provides meals for the children, but breakfasts



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only for adults taking care of the children. Should the adults desire the hospital meals they can buy the vouchers at a cost of 8 euro.

Near the entrance there is a small colorful corner with toys and a small library available to the children and two armchairs where you can sit for a moment of relaxation. There is a shared bathroom for the 2 rooms where you can also dry clothes

### **What to bring to the hospital**

- overalls (or shirts ) with short sleeves, even in winter; it gets very hot at the hospital
- thermometer: hygienic reasons require a personal one even if the hospital personnel use the ear electronic thermometers with disposable covers
- diapers in great number: the operation may easily cause dysentery
- pajamas or overalls (preferably with no feet). Have an old one for the day of the operation: they will ruin it for sure in the operating room.
- stockings and socks
- bibs in large numbers: the operation increases salivation
- all necessary equipment for the baby body care
- all necessary equipment for the baby food
- baby bottles and pacifiers to be used before and after the operation
- a buffer for the baby bed. Hospitals have them but it is better to have a spare one.
- mosquito repellent in summer
- toys for the little patient...a way as any to make him feel less uncomfortable...

### **Admissions**

Usually the admission takes place the day before the operation. Remember to bring all the documentation of your little one. The room is shared with at least one



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other patient. During the day the presence of the two parents is tolerated, but usually at night only one can stay. The child must arrive at the operation with an empty stomach but, usually up to a few hours before you can give liquids. You will be taking the child to a room next to the operating room where the anesthesiologist will send it to sleep. Arm yourself with patience, your baby could wake up changed in a bad mood and irritated; one of the best medicine is to make him feel the warmth of the family and lots of cuddles. Remember to not holding in your arms your baby with face towards you or supported on your shoulder, they have surgical sutures and could be painful or, worst, the stitches could be broken. Also be prepared to measure the corridor, back and forth, back and forth.....it will be the place of your walk and the baby carriage your walking companion. But a week flies quickly and you will be coming home with a new smile.....

## POST -OPERATIVE COURSE

### Visits

Before leaving the hospital, you will be given an appointment for the after surgery visit and a letter to preserve and present at subsequent visits. These visits will become less and less frequent up to once every year.

The families will start the post operative phase with speech therapy sessions, otorhinolaryngologist visits and later on orthodontic treatments. When you are waiting for the check-up visits, while the little ones play, share your experiences with other families, it will be a very simple way help those who are starting now:

**That is the way we did it**



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### **The problems of the ears**

The children with cleft lip or cleft palate, may be subject to the risk of pathologies of the ears due to the frequent tubal dysfunction as a consequence of the palate malformation and of the connected muscles. For this reason, in conjunction with visits to the Smile House, every child is visited by an otolaryngologist (the first room on the left) who, with the help of an audiometrist, will submit it if necessary to a number of specialized tests such as tonal audiometry, nasal endoscopy etc.

To contact the association "Crescere e sentire " that takes care of these aspects, calls 0281844511, 0281844470 or send an e-mail to [segreteria@smilehouse@ao-sanpaolo.it](mailto:segreteria@smilehouse@ao-sanpaolo.it) or [sentireecrescereonlus@gmail.com](mailto:sentireecrescereonlus@gmail.com)

### **Care of the teeth and orthodontic**

Children with cleft lip and palate may need orthopedic and orthodontic treatment with the application of special devices. The children will be supervised by the Smile House orthodontists who can give you all necessary information or give indications to the specialists of your choice. Orthodontists will then assess whether there will be the need to make teeth alignment or widening of the palate, monitor the growth of the maxilla and possibly coordinate with surgeons for surgical corrections. The orthodontic treatments take place on Tuesdays, throughout the day and Thursday afternoons. The orthodontists office for the babies is located in the third room on the left.

To adoptive children with milk teeth already all (or almost) in place special attention, is recommended, immediately after the operation, to take care of oral hygiene and cleaning of the teeth, to avoid any risk of infection and promote a rapid healing.



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### **The problems of the speech**

Children with cleft lip and cleft palate may have problems with the speech. Speech therapists are encouraging parents as soon as possible to interact with children by way of behaviors in line with to the communicative-linguistic development of the child. Later on when the child will start to speak, it is important to continue to encourage expression and socialization, and meanwhile, gradually, you will begin the re-education through targeted speech therapy exercises. The route is of course combined with surgical and orthodontic treatments depending from the extension of the malformation. Sometimes for a better evaluation they will submit a exam with fibroscope and/or X-ray (velografia).

In the Smile House you will find professionals who can help you. Speech therapy sessions take place on Mondays and Thursdays at the Smile House, at the office of the speech therapists located in the fourth room on the left. The room is equipped with games that will be used during the sessions.

### **Psychological aspects**

You will meet psychologists during your first meeting at the Smile House before the birth or the adoption. In some cases it is your family doctor who will ask you to talk to a psychologist but you can also ask yourself directly to psychologists of the team when their office is opened. Meetings and support information will take place at the San Paolo offices situated in viale Famagosta 46, II floor. To make an appointment you must call directly the Psychology Service at the number: 0250323129.



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### The history of the Association

We are a group of parents of children with facial malformations taken care by the Smile House at the San Paolo Hospital in Milan.

By attending the maxillofacial department for the care of our children, we realized the importance and value of the help and relations that develop between the parents of the children being treated.

We started in 2011 to organize ourselves as Parents Group, then considering the many requests and the enthusiasm that our initiatives have raised, in 2013 we decided to establish this association in order to give support to other families facing this task.

We come from all over Italy, we share the stories of our children and their "special" smiles. The stories often last for a few minutes, some other times it takes hours to tell. At the end all the stories turn into friendships and affections as in a big enlarged family, because that's how we feel!

### Our goals and our activities

Encouraging families to share their experiences in order to create a support network for those facing this pathology.

Bring to the attention of the hospitals and their departments any issues related to the

hospital service therefore increasing the dialogue of the families with their doubts and the hospital team

Provide practical information to parents before and after the operation and how these malformations can affect the future of the children

Provide information on the logistics related to hospitals

Organize group activities such as events and seminars

### Join today!

Join the association by filling out and submitting the appropriate form, and you will receive all the information about the activities in support of the families and group gatherings

### Support us

By bank transfer to:

**ASS. TI RACCONTO UN SORRISO**  
**IBAN: IT83J010053371000000000648**

### Contact Us

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