



HELIOS Hospital Schwerin

*A very special baby*

Cleft lip, jaw and palate

Information for parents

# Information

*Healing*

*Expertise*

*Well-being*

*Care*

1. Split emotions	4	5.2. General dentistry	20
2. Only a small scar remains	6	5.3. Orthodontics	21
3. Breastfeeding and diet	8	5.4. Otorhinolaryngology	22
4. Care	11	5.5. Speech therapy	23
5. Treatment	12	6. Further information	24
5.1. Oral and maxillofacial surgery	15	6.1. Costs	24
5.1.1. Nose and lip reconstruction	16	6.2. Travel information	25
5.1.2. Hard/soft palate repair	17	6.3. Accommodation	26
5.1.3. Cleft jaw repair	18	7. Treatment results	27
5.1.4. Follow-up surgeries	19		

## ○ 1. Split emotions

When you first learned of your child's cleft, you may have felt emotions such as shock, disappointment, helplessness and fear.

As understandable and natural as these first reactions are, they will soon give way to love and joy when you embrace your child.

Treatment should be started as early as possible so that your child's cleft will soon be barely noticeable and your child can grow up without any disadvantages. Ideally, it should be done so early that soon neither you nor your child will even remember it.

All those medical appointments and, in particular, surgeries into adulthood will become a thing of the past.

The great efforts needed to take care of everything within the first year of life will be rewarded with your child's happy laughter.

We recommend an individual consultation with us. We can analyse your case with you and answer all your questions via Skype or video consultation.

We look forward to talking to you. Together, we can develop an individual treatment concept for your child.

*Your oral and maxillofacial surgery team*

### Our treatment goals

- Natural appearance
- Normal speech
- Problem-free chewing





## ○ 2. Only a small scar remains

Most clefts can be fully repaired and only leave a more or less unnoticeable scar.

The types of clefts may vary significantly.

Depending on the stage of embryonic development during which the malformation occurred, there are different types and levels of severity

- Cleft lip
- Cleft lip and jaw
- Cleft lip, jaw and palate
- Cleft palate
- Submucous cleft palate

Clefts can be unilateral or bilateral, incomplete or complete.

In rare cases, hidden clefts may be barely palpable under the skin or mucous membrane.

Then the cleft frequently will not be discovered until it begins to affect speech development because of the dysfunctional muscles under the closed layer of skin.

The wide variety of possible clefts requires an individualised approach tailored to your child's needs. Only then can we achieve the best possible results.

Even though different types and levels of severity may be present, your child will very soon look like any other and will develop in a completely normal way.

We will need photos for the consultation. You can take these at home using your smartphone or a camera. Ideally, the pictures should show all affected areas from different angles, such as a frontal view of the face and views from above, from below and from the side, or the jaw/palate.

**Tip:**

When your baby gives a big yawn, you can get a good shot of the palate using the camera flash.



Cleft lip



Cleft lip and palate



Cleft palate

### Locations where a cleft can occur

- Lip: upper lip up to the tip of the nose
- Upper jawbone
- Hard palate (bony portion of the palatine arch and the nasal floor)
- Soft palate (back portion of the bony palate up to the end of the uvula)

## ○ 3. Breastfeeding and diet

If you would like to breastfeed your baby, you will need plenty of time and patience. Breastfeeding may be problematic because the muscles of the soft palate are affected by a cleft palate, preventing your child from creating a sufficient vacuum. In particular, the child will lack the necessary strength to drink enough. As a result, your child will drink much more slowly and with greater effort and will tire very quickly.

That is why the remaining breast milk often needs to be expressed and given to your baby in a bottle. Your midwife will be happy to assist you with that.

Normal bottle teats are also often a problem for children with a cleft. If you give your baby breast milk and formula in a bottle, you can choose from a variety of bottle teats and need to pick the one that is best suited for your child. They come in a wide range of shapes and you will soon find out which one works best for your child.

Some special bottle teats are available in pharmacies, others in any drugstore.

The Haberman feeder, for example, makes drinking easier for many children by simply adjusting the size of the slit valve opening and gently squeezing to keep the milk flowing. On the other hand, the muscles of the mouth are challenged to a lesser extent and are thus not trained. This means that you can lightly stroke the teat with your hands to prevent your baby from tiring too quickly. In general, you should expect to spend 15 to 30 minutes of extra time every time you feed your baby.

Don't worry when liquid is running out of your baby's nose while feeding. This is neither unusual nor dangerous and will only stop once the essential surgeries are completed.

This NUK First Choice teat, for example, is characterised by its orthodontic shape as well as the wide, soft and elastic lip support.

You need to find the teat that works best for your baby.





## ○ 4. Care

Apart from a few special aspects, there is no need for you to be overcautious when caring for your child.

You should bath and care for your child just like you would any other child.

In particular, the area of the cleft may be washed and cleaned just like any other body area. The cleft is not a wound, so it does not hurt your child. Leaving this area out would irritate the child.

Please clean the lips and the jaw using a cotton swab and baby oil or Vaseline several times a day to prevent unsightly incrustation or even infections. Such incrustation often results from dryness of the mucous membranes which are normally wetted with saliva.

Once the first few teeth come through, you need to start with tooth-brushing. Your child's teeth should remain free of caries. The central and lateral incisors of children affected by a cleft often exhibit impaired mineralisation in the form of yellowish-brownish spots. This is not caries and results from insufficient blood supply. You should nevertheless take precautions to prevent caries.

Until the milk teeth come through, you can support mineralisation with fluoride tablets, possibly in combination with vitamin D.

## ○ 5. Treatment

First steps in the right direction to stimulate healthy growth: Send us a treatment request, either before the delivery with an ultrasound or right after birth. Take the photos as described on page seven and send them to us by email. We can then arrange a video consultation on short notice. We will provide you advice and organise all the necessary steps for your baby to undergo surgery within the next few weeks. We will also show you in the video consultation how to tape the lips with adhesive plaster strips. Once the nutrition of your child is ensured, the trip to us can be organised.



### Information on the treatment

Today's improved and gentle anaesthetic techniques permit surgeries without a high risk as early as a few weeks after birth.

Atraumatic surgical techniques using the surgical microscope have also been improved to such an extent to enable increasingly better results in terms of both appearance and function.

This means that your child will have completed all essential procedures within the first year of life.

This requires commitment and comprehensive care by both the parents and the team experienced in the treatment of clefts in collaboration with various medical disciplines:

- Oral and maxillofacial surgery
- Paediatric intensive care medicine
- Paediatric medicine
- Otorhinolaryngology
- Orthodontics
- Speech therapy



### Your point of contact

**Prof. Dr. Dr. Reinhard Bschorer**  
Oral and Maxillofacial Surgeon  
Plastic Surgery, Oral Surgery

### We aim to achieve three treatment goals:

- Restoring the appearance and harmony of the face
- Restoring the normal function of the lips, cheeks, tongue as well as the hard and soft palate
- Repairing the cleft within twelve months



## ○ 5.1. Oral and maxillofacial surgery

The number of surgeries depends on the type and the extent of the cleft as well as on the result of the first treatments.

Most children are affected by a combination of several defects and the simultaneous repair of all defects within one surgery is not always possible.

During the inpatient stay, you can stay with your child at our hospital. We have a very convenient mother-child centre with an upscale interior.

Our doctors will always keep you informed of the course of your child's treatment.

However, please be prepared that after the surgery the lip and nose area will still be bloody and swollen, your child may have a feeding tube and a bandage around the mouth and the nose and the arms will be fixed with arm restraints or wraps. But those days will pass by in a flash. And you will be able to see the result immediately after the surgery.

### Requirements for inpatient admission

- Your baby should be healthy in the weeks prior to the surgery. Even if it is just a common cold, we prefer to postpone the surgery until the child has completely recovered.
- Your child will undergo a general paediatric physical examination at our hospital
- Anaesthesiological examination to assess the fitness for anaesthesia and surgery
- Informed consent to the surgery/anaesthesia

## 5.1.1. Nose and lip reconstruction

Nose and lip reconstruction is performed from the age of four weeks. Important criteria for best possible surgery results include the type and extent of the cleft as well as the tissue-conserving microscopic technique to enable rapid healing.

Depending on the healing process, the sutures and the nose pads are removed after six to eight days. The sutures are so fine that they need to be removed under the microscope under short anaesthesia. It is important to know that the final appearance of the small scar

in the area of the upper lip will only become apparent after six to twelve months. By that time, the scar will have faded and smoothed.

### Important for scar treatment:

- Scar check
- Scar ointment
- If necessary, laser therapy

We can discuss all this in a video consultation when you are back home again.

## 5.1.2. Hard/soft palate repair

In general, surgical hard and soft palate repair takes place at the age of six to twelve months.

It will certainly take a few days, but children usually learn very quickly how to move the soft palate. The separation of the oral and nasal cavity immediately facilitates feeding and speech development, which starts as early as the age of 8 months. Clear articulation allows the baby to hear their real voice and develop sounds and speech in the further course of their life.

If this closing mechanism still does not work properly, e.g. due to a large distance to the retropharynx, a speech therapist can be consulted to analyse whether proper closure can be achieved by means of a speech therapy or whether a so-called speech-correction surgery needs to be performed at the age of four to five years.

### Surgery

1. Correcting the nostrils and the tip of the nose (to prevent further malformation)
2. Connecting the individual layers of the lip:
  - Mucous membrane on the inside of the lip
  - Orbicular muscles of the mouth
  - Restoring the mobility of the mouth and the outer skin
3. Shaping the nasal vestibule, the front nasal floor and the tip of the nose (to adapt the shape of the nose – sometimes requires the insertion of special nose pads)

### Surgery

1. Repairing the cleft soft palate by connecting the swallowing and speech muscles of the soft palate (to restore the functions of the soft palate which are important for speech development)
2. Suturing the mucous membrane at the centre of the palate to prevent food particles from entering the nose

### 5.1.3. Cleft jaw repair

Cleft jaw repair is performed at the age of six to twelve months. Together, we determine the best possible approach for your child.

The size of the cleft is given particular attention. Depending on the size of the cleft, different techniques/materials are used to repair the cleft jaw:

- Suturing the periosteum (new bone can form)

- Introduction of synthetic bone replacement material
- Introduction of growth factors

All these measures differ more or less strongly, but they all aim to achieve the same goal – to enable the milk teeth to move into the newly created foundation, i.e. into the former cleft. They then form the lead structure for the later permanent teeth.

#### Surgery

Creating a bony foundation for the milk teeth around the cleft



### 5.1.4. Follow-up surgeries

Not every child needs a follow-up surgery. This depends on a number of factors, such as the width of the cleft and the healing process.

#### ○ Speech-correction surgery

If there is a large distance between the retropharynx and the soft palate, proper closure is not possible and your child will thus not be able to speak clearly despite extensive speech therapy and great efforts. In most cases, this is the consequence of a late or non-microscopic surgery, where the muscles were sutured together inaccurately.

In such cases, a speech-correction surgery should be performed before school entry.

Otherwise, language acquisition and thus school readiness may be affected.

The surgical procedure creates additional muscle forces to the uvula, allowing the children to speak clearly and effortlessly after surgery. In most cases, the children are able to speak without any effort as early as directly after the surgery.

Additional corrective measures may be necessary to optimise the aesthetic and functional result.

#### Surgery

Relocating the mucous membranes and muscles from the retropharynx to the soft palate (creation of additional muscle forces)

## ○ 5.2. General dentistry

Because of the changed blood flow, teeth near the cleft are more often affected by enamel changes and caries. However, caries can be avoided. By following a few simple rules, you can spare your child a painful visit to the dentist

Prevention is much more effective and comprises, in addition to consistent and careful dental care (preferably after every meal), various types of fluoride prevention, which is particularly important for children with a cleft, as well as a healthy diet.

Do not let your child get used to extensive sugar consumption in the first place! Do not use sugary beverages or sweetened baby foods and only give sweets along with the main meals.

Regular visits to the dentist help recognise any enamel changes at an early stage. Always use fluoride toothpaste. We also recommend that vitamin D prevention be combined with fluoride and that fluoride tablets be taken into adolescence.

This helps harden the enamel of the teeth adjacent to the cleft.

When the milk teeth come through, it is an important event for your child and the whole family. Milk teeth also need to be cleaned thoroughly.

Your child should get used to the toothbrush as early as possible. Therefore, clean your child's teeth together.

Let your child hold a toothbrush so that they can get a feeling for it in a playful way. Keep at it until your child properly cleans their teeth on their own after every meal.

Bear in mind that teeth are important for the growth of the jawbone, which is not completed until the age of 16 years. If teeth are lost early or if there are too few of them, increased efforts and orthodontic procedures have to be expected. Later on, dental implants may be needed to close the gap.

## ○ 5.3. Orthodontics

Not every child needs orthodontic treatment. It can be performed at various stages of development, depending on age and tooth condition.

### ○ Oral and maxillofacial surgery/ Orthodontic treatment with a feeding plate

A feeding plate is used to create a new artificial palatine arch. The treatment is carried out including regular readjustments and check-ups and is continued until the hard palate is repaired, i.e. until the second surgery.

### ○ Orthodontic treatment in early childhood

After the milk teeth have completely come through, removable orthodontic appliances can be inserted into the deciduous dentition to counteract existing scar contractures that may entail malocclusion. This orthodontic treatment in early childhood is continued until the mixed dentition stage.

### ○ Treatment at the mixed dentition stage

The third stage for a possible orthodontic treatment commences during the second dentition. X-ray examinations are performed to check whether all or excess teeth are present in order to determine the accurate orthodontic treatment concept until completion of tooth development. Your orthodontist will be able to treat your child with a wide range of removable and fixed appliances.

We will be happy to consult with your orthodontist concerning these options.

## ○ 5.4. Otorhinolaryngology

As a result of the cleft in the soft palate, the connection between the middle ear and the soft palate (Eustachian tube) can no longer be opened, entailing collection of fluid and potential infections.

Your child is not able to ventilate the middle ear, i.e. to equalise the air pressure, which may frequently entail otitis media or serous otitis media.

Serous otitis media involves the collection of fluid behind the eardrum, affecting the auditory capacity and consequently the entire development of your child. To avoid such developments, the ears should be

examined on a regular basis. From the age of three months, objective audiometry should be conducted.

A puncture of the eardrum can be performed simultaneously to the cleft lip repair. This means making a small opening in the eardrum and placing a tympanic cavity wash tube to discharge the fluid behind the eardrum and ensure ventilation of the middle ear.

In the event of chronic serous otitis media, the wash tube, which falls out after about half a year, needs to be replaced regularly until the infection is completely cured.

## ○ 5.5. Speech therapy

Speech development commences as early as the first months of life, when the baby starts to make babbling sounds. Hearing these sounds causes an auditory feedback loop and a few months later your child will try to imitate sounds from the environment.

To promote speech development and general social development, we recommend early repair of the cleft soft and hard palate and corresponding speech therapy.

The goal of normal speech development until school entry will be monitored by us as well as the accompanying speech therapist in order to be able to perform a timely speech-correction surgery, if necessary.

Parents can also contribute to speech development:

- Use every occasion to comment your activities (changing nappies, washing, playing, shopping, etc.)
- Keep eye contact while talking.
- Always let your child finish speaking so that they can find their own speech tempo.
- Be a good role model: avoid “baby talk”, speak slowly and clearly and use simple short sentences.



If your local speech therapist no longer sees any progress in speech development, you should get in touch with us again. Independently, a medical examination,

if necessary including a video consultation, should be performed once a year, at least until school entry.

## ○ 6. Further information

You would like to have your child treated at our hospital? The multilingual team of the HELIOS International Office will be happy to help you plan your trip to Germany.

### Medical treatment

We need you to provide us with the following documents in advance:

- Complete physical examination of your child
- Photos, ideally from all angles

## 6.1. Costs

We provide individual cost estimates based on the patient's information and treatment recommendations given by our medical specialists. The entire cost structure is based on the German DRG system, the official billing system used in Germany.

**In addition to the general costs of medical treatment, costs may be incurred by making use of optional services.**

- Accommodation costs: You can choose between a single or double room on the optional services ward. Accompanying persons can be accommodated in the patient's room.
- Costs of treatment by private physician: You will receive treatment from the chief physician or his deputy. The treatment by the chief physician will be charged on the basis of the statutory Medical Fee Schedule (GOÄ). This also includes all accompanying medical services, such as anaesthesia, laboratory medicine, etc., which will also be charged separately.

**Before your arrival, we expect a prepayment of the treatment costs (medical treatment as well as optional and other services) to the total amount stated in the cost estimate.**



## 6.2. Travel information

### Planning the treatment

We support you in organising your trip to Germany and obtaining the necessary documents (visa, flight, accommodation of the patient and relatives, transfer, interpreter services, etc.).

### Arrival

We help you book your flight or hotel and organise your transfer from the airport or railway station. Upon request, we can refer you to our partners with whom we have arranged special conditions.

### Visa information

Depending on your home country, you may need a visa to enter Germany. We will be happy to help you obtain your visa by issuing a corresponding invitation letter for you and your relatives.

To this end, it is important that you send us a copy of your passport beforehand. In addition, most embassies expect that the treatment costs be clarified in advance and that a transfer voucher of the estimated treatment costs be attached to the invitation letter. You can apply for a visa with the invitation letter at the German embassy of your home country. You are only allowed to enter Germany with a valid visa.

### Interpreter service

Our interpreters have many years of experience in supporting patients at our hospitals. This means that they not only provide language support but also help you find your way around the hospital and find the right points of contact.



## 6.3. Accommodation

A specially developed facility concept just for you! In our hospitals, you find a pleasant environment that will help you to relax and get well soon. Rooms designed with warm colours combined with highquality materials create a sense of wellbeing and comfort.

### Room amenities:

- Comfortable single or double room
- Electrically adjustable multi-position bed
- Separate bathroom with ground-level shower, heated towel racks as well as hair-dryer and vanity mirror
- Terry bathrobe, bath towels and towels, cosmetic bag with toiletries
- Telephone without basic charge
- Flat-screen TV
- Wireless Internet connection

### Services & Catering

- Large selection of high-quality meals and varied menu service
- Selection of fresh fruit and cakes every day

Our service staff will take care of everything you need and fulfil all your culinary wishes. Our service concept is characterised by instant information, support exactly when you need it and loving attention to detail.

### After your treatment

It is our common goal to present the final bill on the day of your discharge. We will be happy to support you in planning your trip back home and – if necessary – your aftercare. You will receive the physicians report by email.

**Should you have any questions, please do not hesitate to contact our multilingual team of the HELIOS International Office.**

## ○ 7. Treatment results



### Cleft lip

- Surgery in the 1st month of life, microsurgical nose and lip reconstruction including correction of the nostril



### Cleft lip and jaw

- Surgery in the 2nd month of life, microsurgical nose and lip reconstruction including repair of the nasal floor



### Cleft lip and palate

- Surgery in the 2nd month of life, microsurgical nose and lip reconstruction including correction of the nose
- Surgery in the 6th month of life, soft palate repair
- Surgery in the 11th month of life, hard palate repair including cranial osteoplasty



### Bilateral cleft lip and palate

- Surgery in the 2nd month of life, microsurgical nose and lip reconstruction on both sides
- Surgery in the 5th month of life, soft palate repair
- Surgery in the 13th month of life, hard palate repair
- Surgery in the 3rd year of life, velopharyngoplasty



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