

Patient information

Cleft lip and palate / Prenatal diagnostics and support during pregnancy

We provide comprehensive cleft treatment, bearing all influencing factors in mind. We also strive towards single-stage cleft closure whenever possible (so called "one-stage" cleft repair). Consultation and care is provided right from the beginning in cooperation with all involved specialties:

- prenatal diagnostics and support during pregnancy
- postnatal care and support after pregnancy
- insurance benefits
- surgeries
- outpatient follow-up

Investigations and treatment

Prenatal diagnostics and support during pregnancy

At the University Hospital of Basel, 3D ultrasound examinations are performed during pregnancy to detect any signs of a malformation. The interdisciplinary team is directly involved in cases of suspected cleft lip, jaw or palate, beginning with the ultrasound examination. The parents thus receive detailed information during the consultation session. Personal contact with the midwife, lactation counseling from the maternity unit and interaction with the involved surgeon helps provide information about the disease, its therapeutic approach and the further course of action before and after delivery.

Postnatal care and support after pregnancy

The delivery takes place, if possible, at the Women's Clinic of the University Hospital of Basel or, for patients insured in Germany, at the St. Elisabethen Hospital in Lörrach. In case of delivery at another hospital, an early transfer to the maternity unit at the Women's Clinic of the University Hospital of Basel is also possible. The mother and child are not separated. Treatment is provided at the Cantonal Hospital of Aarau for children from this region with their maxillofacial surgery experts working in collaboration with us. The newborn is cared for together with the mother at the maternity unit after delivery. Parents learn how to care for and feed their child under the guidance of nursing staff and with the aid of lactation counseling. In case of a complete cleft palate, a palatal plate is made to cover the cleft within the first few days of life. The tongue thereby gets accustomed to a normal form of the oral cavity even without surgery. This prevents the habit of placing the tongue in the cleft. It helps promote early development of correct movement patterns in order to enable feeding and lays the foundation for later speech development.

Newborn babies with a cleft lip or cleft lip and jaw may usually be breastfed. It is possible to place the newborn on the breast the first time immediately after birth even with a pronounced cleft. The mother is instructed by breastfeeding counselors on the usage of a milk pump if breastfeeding is unsuccessful, so the newborn may receive healthy pumped milk from the mother. Newborns with an accompanying malformation, such as the Pierre Robin sequence, are nearly always admitted to intensive care for monitoring in the first few days to be on the safer side, where they are cared for until they can breathe normally. One of the parents may also stay with the child at all times in the intensive care unit.



Insurance benefits

Parents must <u>register</u> the child after birth for disability insurance in the canton of their residence. It is necessary to register for medical procedures for underage children. This registration form can be filled out on paper or <u>electronically</u>. If we are specified as the treatment team during this registration, the disability insurance will obtain medical details about the diagnosis of cleft lip, jaw or palate, and assign a so-called approval number to your child after verification. Thereafter, the hospital will bill the disability insurance directly using this approval number and there will be no deductibles for you. A compensation of travel costs to and from treatment appointments may also be requested for a companion (Form 4.05 Compensation of Travel Costs during Disability).

All forms of cleft lip, jaw and palate are recognized birth defects and the costs of their treatment are covered by disability insurance until the age of 20. Cleft lip, jaw and palate are listed under Birth
Defects No. 201.

Please note, there is an important exception. The disability insurance does not pay for speech therapy, so these costs must be submitted to the health insurance. In this context, it may be advisable to procure a supplementary insurance in order to claim complementary medical options (e.g. myofunctional therapy, which treats muscular interactions in the entire body), in addition to speech therapy, if needed.

Surgeries

Early cleft closure is important to enable virtually normal speech development. According to the Basel Concept, complete clefts are always assessed individually with treatment being planned based on the extent of the cleft, and preliminary treatment is provided using plate and plaster therapy for instance. Definitive closure of lip and palate usually takes place in one single surgery (syn. one-stage cleft repair). It is performed at the age of about 6–8 months, ideally when the child weighs over 8 kg, and depends on the width of the cleft and the form of the jaw. The single operation concept is not followed in some cases with complete bilateral cleft lip, jaw and palate with a premaxilla that protrudes far anteriorly. In these cases, the lips are preliminary stitched before the lip and palate are definitively closed. Only the skin edges of the lip from either side of the cleft are stitched together without repair of the lip muscle, this procedure is known as lip adhesion. These skin edges must in any case be removed during the final surgery. No additional scars therefore develop. The elastic force of the lip skin results in a harmonious development of jaw segments, which improves the starting point for definitive closure such that a gentler surgery can be performed.

If the part of the bony maxilla (alveolar process) that holds the teeth is split, as in cleft jaw, the bone is not inserted in to this area during the first surgery in infancy, because it will not grow along with it. The bone is inserted only before the permanent teeth erupt on either side of the cleft. Bone marrow rich in cells is taken from the inside of the iliac crest for this procedure. The bone marrow is placed in the cleft and the adjacent mucosa closed over it, so that the bone may heal. Nothing is visible or palpable at the sampling point except for a short linear scar. This procedure must be performed under general anesthesia. In most cases, the intervention is performed shortly before starting school at about 5-6 years of age.

All surgical procedures in children under the age of 16 are performed at the University Children's Hospital Basel (UKBB) and, for children with German insurance, at the Elisabethen Hospital in Lörrach. For parents who live far away, convenient accommodation for parents at the Ronald McDonald Children's Foundation may be requested for during the duration of the child's hospitalization and is located in the immediate vicinity of UKBB.



In the operating room

The parents may accompany the child until anesthesia induction. The anesthetist makes the preparations for surgery. After anesthesia induction, surgery is usually initiated by the ear, nose and throat (ENT) surgeons. The ear is examined through the microscope. If a middle ear effusion is present, it is extracted through an incision into the eardrum (paracentesis). To ensure that no further secretion accumulates, a drainage tube is usually inserted into the eardrum (tympanic drainage). Surgery for cleft closure begins thereafter. No foreign material is sutured in, and instead the child's own tissue on the right and left of the cleft is moved to the center and sutured together: skin to skin, mucosa to mucosa, and muscle to muscle. The direction of movement of muscles, incorrectly developed due to the malformation, is corrected, so that the lip and soft palate can move correctly. Self-dissolving sutures are used in the oral cavity so they do not need to be removed. On the other hand, sutures used on the lip do not dissolve, leaving a fine scar. Sutures on the lip are removed after 7 days (under sedation).

The child is moved to the intensive care unit (ICU) or directly back to the inpatient ward after surgery. The final decision regarding this is made by the anesthetist during surgery. The child is usually monitored in the intensive care unit for the first night after the surgery after closure of a complete cleft lip, jaw and palate or a complete cleft hard and soft palate. One of the parents may also stay with the child overnight in the intensive care unit.

While the child is under anesthesia, not being able to be with them is difficult. If you wish, a contact person may be made available to you during this time who may be in direct contact both with you and with us in the operating room, and inform you about the progress of surgery.

Pain treatment

The child receives an infusion for pain relief and sedation in the first 24-48 hours after surgery. There is no further need for infusion once the child begins drinking enough on his own and painkillers are then administered in suppository form. Children mostly start drinking enough again on the second or third day after the surgery. A gastric feeding tube is therefore usually unnecessary. Children with a cleft palate receive an antibiotic for three days.

Fluid intake

The child is first administered fluid and glucose by infusion. The child may be breastfed or receive milk in the Haberman Feeder or a drinking cup after surgery. The Haberman Feeder is a special drinking bottle for infants with suction problems. The baby may use it to drink without having to create a suction vacuum. The child may be discharged as soon as he or she begins drinking well and pain medication no longer needs to be administered by infusion.

Stitch removal from the lip

Stitches on the lip are removed after 7 days by the surgeon. Usually, the child has already been discharged and sent home, so this is done on an outpatient basis (the child returns home the same day).



Outpatient follow-up checks

After surgery, weekly wound inspection is done until the wound heals completely, which usually takes about four weeks.

In case of cleft lip repair with a clearly laterally displaced wing of the nose, soft silicone tubes are inserted into the nostrils, around 2 weeks after surgery and are applied for the following 4 month. This counteracts contraction of scar tissue and ensures good opening of the nostril for nasal breathing. The tubes must be cleaned and reinserted by the parents daily as instructed.

Follow-up examinations are performed twice a year until the age of two in order to monitor the initiation of speech development. Annual or biannual follow-ups are usually performed thereafter with a special focus on lip and tongue movement, nasal breathing, speaking, tooth position and jaw growth. Various specialists are therefore present in the special out-patient clinic and make a joint assessment to enable mutual agreement on further therapeutic measures (oral and maxillofacial surgery, speech therapy, orthodontics). The ears and hearing are also examined by an ENT specialist in children with a cleft palate. Children are usually invited to interdisciplinary cleft clinics until growth is complete and they turn 20 years old. Parents may get in touch with the team at any time in case of doubts, questions or concerns and make an interim appointment.