Parent Information Packet

For

Midface Distraction Osteogenesis

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Midface Distraction Osteogenesis

The midface of a person includes the upper jaw (maxilla) and some portion of the cheek bones (zygomas). In a number of craniofacial conditions, the midface does not develop in a child at the expected rate (midface hypoplasia), leading to a number of problems. The most common concern is difficulty with nasal breathing (nasopharyngeal stenosis), which can prevent a child from receiving the sleep they need to grow (sleep apnea). Other problems include poor protection of the eyeball (corneal exposure), difficulty handling body fluid produced at the back of the throat (nasopharyngeal secretions), and the upper front teeth biting behind the lower front teeth (class III malocclusion). Midface hypoplasia also results in a concave, or C-shaped, appearance of the face when the person is viewed from the side.

The only way to treat severe midface hypoplasia at this time is an operation to make a cut in the bones of the face at specific points, loosen the midface from the rest of the skull, and then advance it into a more correct position. Until recently, the midface had to be secured in its new position at the end of the operation using bone from other parts of the body, such as rib or skull (autogenous bone graft), as well as plates and screws. This midface advancement operation has been very successful in treating midface hypoplasia over the years, however distraction osteogenesis can now be used in certain patients to improve the technique.

Distraction osteogenesis is a technique that was used by an orthopedic surgeon shortly after World War II to lengthen bones of the legs, or treat bones that would not heal. The principle of distraction osteogenesis is that a cut is made in a bone and then allowed to start a few days of early healing. The healing tissue (regenerate) in the cut is then slowly and gradually stretched, or distracted. After the bone is in the desired position, it is held in place and the regenerate tissue is allowed to heal by turning into new bone. In this way, a longer bone is formed from a shorter one.

In 1992, distraction osteogenesis was performed successfully on a human lower jaw (mandible), and since the mid-1990's, it has been used to treat midface hypoplasia. It is no longer an experimental procedure. It is performed at major craniofacial centers across the country with FDA approved distraction devices.

There are a *number of advantages* of midface distraction osteogenesis over the older technique:

1. Bone grafts are not needed to hold the bone in place. This avoids the problems and pain that can occur with operating on another part of the body.
2. Larger advances of the midface are possible than with traditional techniques. This is because the skin and muscles on top of the bone are slowly stretched along with the bone. This allows the face to adapt to the new position of the bone, and not try to push it back as much.
3. Although variable, the duration of the operation is less with distraction osteogenesis.

There are a *number of disadvantages* of midface distraction osteogenesis compared to the older technique:

1. With distraction osteogenesis, a light metal 'halo' device and a dental splint must remain in place after the operation as the bone is stretched then allowed to heal (about 10 weeks).
2. A short second operation under anesthesia is required to remove the halo and splint. This is a day surgery, with discharge the same day.
3. With distraction osteogenesis, a caregiver in the home must be responsible for turning the distraction device twice a day for one to two weeks. Although this is very easy to learn, it must be done reliably.
4. Distraction osteogenesis requires one small ($1/8^{th}$ of an inch) scar on each lower eyelid that are not needed with the older procedure. These tend to heal extremely well, however they are a scar and will be easily visible during the healing process.

There are a number of things *that are the same* between distraction osteogenesis and the traditional surgery:

1. Other than the small lower eyelid scars, the scars are the same
2. The location of the breaks in the bones are the same
3. The loss of blood, risk of infection and other complications are the same
4. The duration of the hospital stay, including the ICU, is the same.

To perform midface distraction osteogenesis requires teamwork and cooperation between the patient, parent or caregiver, and the CHRMC distraction team. It is a very successful procedure in the appropriate patient and situation. We look forward to answering any questions you have about distraction osteogenesis at your next clinic visit.

The Rigid External Distraction (R.E.D.) Device

- Distraction osteogenesis of the midface can be performed by either internal (underneath the skin) or external (outside the skin) devices.

- Having had experience with both types of devices, at CHRMC we currently use an external device for midface distractions. We feel that this gives us the reliable results, control of bone movements, and ease of device removal that we are seeking. We are happy to discuss the pros and cons of internal vs. external distraction devices at your clinic visit.

- The distraction device that we currently use is the *R*igid *E*xternal *D*istraction, or R.E.D. Device (even though it is purple in color). It was developed by John Polley, a craniofacial surgeon, and Alvaro Figueroa, a craniofacial dentist, in cooperation with the medical company KLS Martin. The distraction team at CHMRC has no financial interest in the production, sale, or use of the R.E.D. device.

- The R.E.D. device is supported by a cranial halo, similar to the one used to stabilize necks after surgery or accidents. This semicircular piece of light metal encircles the front a patient's forehead and is secured to the skull using pins. The pins touch the bone, but do not go into the bone. The halo is painless as long as the pins are not loose.

- From the halo, a vertical piece of graphite is attached, which has two horizontal beams. One beam is level with the cheekbones, and the other with the base of the nose. The beams are about one to two inches in front of the face. On the end of each beam is a screw with an attached wire. For the upper beam, the wires attach to screws on the cheekbones through small skin incisions. The skin incisions are about $1/8^{th}$ of an inch in length, and are located at the junction of the lower eyelid and cheek. For the lower beam, the wires attach to a dental splint that has been secured to the upper teeth.

- After the surgery to mobilize the bones of the midface, the screws are turned at home twice a day to very slowly pull the midface forward. The upper wires pull the cheek bones forward, and the lower wires pull the upper jaw forward. This "distraction" occurs very slowly, around 1 mm a day, and is not painful. The benefit of the R.E.D. device is that it can easily be adjusted by the physician in the clinic to fine tune the direction of the distraction.

- The R.E.D. device remains in place for the duration of the distraction and healing (around 10 weeks). It is easily removed along with the splint in a day surgery procedure.

Turning the Distraction Device

- Only turn the distraction device as instructed by your physician. Missing a turning, or turning too much can have serious consequences.

- If you miss one turning by mistake, make it up as soon as you remember, then perform the next turning at the regular time.

- Follow the turning protocol below each time:

1. Pick a convenient time at the beginning of the day (morning distraction) and at the end of the day (evening distraction). Each screw will be turned once at each distraction time.

2. Start at the same screw each time (recommend the top right at the two o'clock position).

3. Place the purple screwdriver over the screw with the flat surface of the handle facing up.

4. Turn the screwdriver clockwise (to the right, in the direction of the arrow) ***one complete turn***. You will know when the turn is completed when there is a small click (not always felt), or the flat part of the screwdriver handle is on the top again. Slide off the screwdriver.

5. Repeat step 4 on the next screw. We recommend working clockwise (i.e. bottom right screw next).

6. Complete one complete turn on all the screws, unless instructed by your physician.

7. Check the tightness of the halo pins by turning each pin very gently (two fingers only) clockwise. Stop if any resistance. Inform CHRMC is the pins are loose.

8. Repeat Steps 2 to 7 for the evening distraction.

Phases of Midface Distraction

1. Operation:

- The cuts (osteotomies) are made in the bone to mobilize the midface. The splint and halo are attached and connected by wires. The patient leaves the room asleep and with a breathing tube (intubated)

2. ICU stay:

- The patient must slowly awake before the breathing tube can be removed (extubated). This is a difficult time for the patient, parents and ICU staff. It involves a balance between making the patient comfortable and allowing them to wake up enough to control their airway. Any attempt to rush this phase is extremely dangerous. There will be times during the first night when your child is agitated because they are starting to wake up and don't like the breathing tube. They are typically uncomfortable but not in pain. If the breathing tube is removed at this time, before the child is fully awake, the stimulus of the breathing tube will be gone and they will fall back into a deep sleep and be unable to control their breathing. Please be patient with the ICU staff during this difficult time – their decisions are always based on your child's safety. You can help by touching and talking to your child to reassure them that you are there.
- The time of removal of the breathing tube (extubation) varies from child to child, but typically occurs the first day post-op. On rare occasions a second day of intubation is required.

3. Ward Stay:

- Your child will be transferred from the ICU to the ward after the breathing tube is out, and the ICU staff and surgical staff are comfortable that they do not require ICU level nursing care.
- In order to be discharged, your child's pain must be controlled by oral medications (pills), and they must be able to drink and eat enough to remain healthy.
- It is sometimes difficult to distinguish pain after the operation, which requires pain medication, from irritability that follows all head surgeries, and requires time and reassurance. The nursing staff are trained and experienced in making these decisions.
- The ward stay varies, but typically ranges from one to three days.
- During the ward stay, you will be instructed how and when to start turning the distraction device (usually five days post-op).
- On discharge from the ward, you will receive prescriptions for antibiotics and pain medications, and a date for the follow-up appointment. ***Make sure that you are seen by a member of the CHRMC distraction team within seven days of discharge.*** A delay in follow-up can be very dangerous.

4. Distraction:

- Five days after the operation, you will start turning the four screws on the device clockwise twice a day. Follow the turning instruction carefully. This is the most important time of the procedure. Make sure you stay in close contact with the CHRMC distraction team. You will typically be seen once or twice a week during this time.

- During the early part of turning, your child will be moody and will complain. They will be swollen and want the device off. Their mood will improve significantly after the first week.
- On each clinic appointment your physician will inform you of any changes in the turning protocol. The movement of the bone will be followed by x-ray and clinical exam. Typically four to five x-rays are required – before the operation, on discharge from the hospital, during the turning, and after the healing phase.
- The distraction, or turning phase will vary from one to three weeks.

5. Consolidation:

- After the bones are in the desired position, the distraction device and splint must stay in place to hold the bone as it heals. This is called consolidation, and typically last 8 weeks (2 months). During this period, you will only need to make two or three visits to the hospital unless there are problems.

6. Removal:

- After the bone has healed, the halo and splint are removed in day surgery. A follow-up appointment will be made.
- Small "touch-up" surgeries that may improve the final result of your child's surgery can often be performed at this time.

Homecare Instructions for Midface Distraction

1. Hygiene:

- Start supervised bath with shampoo after discharge from hospital. Do not submerge the distraction device; use shower attachment or a container to gently pour the water over the hair.
- On discharge from hospital, begin cleaning teeth with a very soft tooth brush and water. A very small amount of toothpaste can be used. Do not use mouthwash, oral rinses, or sponges.
- Beginning post-op day #6, apply warm towels to cheeks. Apply them as much as possible throughout the day.

2. Device Care:

- Do not touch the wires, splint, or frontpiece of the device unless instructed by your physician
- Check the pins daily by *gently* turning clockwise. Use only two fingers. If they are loose, inform your physician or nurse. Do not try to tighten them yourself.
- It is common for your child's lips to become dry. Immediately post-op you can apply Vaseline or other non-medicated lip ointments to the lips.

3. Diet:

- You must expect some temporary difficulties in feeding your child by mouth after the operation. With some practice, they will learn to use a straw and spoon to work around the splint.
- The diet must remain soft for the entire time the device is on. After leaving hospital, a good rule of thumb is anything that can be easily squished with your fingers is soft enough. This can include over-cooked pasta, or vegetables. Try to be imaginative. Some children who have missed the taste of their favorite pizza, enjoy a blenderized portion.

4. Medications:

- Follow the prescriptions given to you by your physician.
- Take the liquid antibiotic as ordered until all of it is finished.
- Children's liquid acetaminophen (Tylenol) can be used as recommended on the box if your child is in mild discomfort.

5. Activity:

- Walking and sitting upright are important for healing and a decrease in swelling.
- Initially your child may only want to sleep on their back to avoid touching the device, however any sleeping position is acceptable.
- No sports or physical games is allowed until approved by the physician
- Minimize unsupervised play with other children as much as possible

6. Things to watch for (call your nurse or physician):

- Loosening of the device, splint or pins
- Redness or discharge (pus) around the pin sites
- A persistent fever, headache or visual disturbances
- A fall or blow to the device
- An increase in swelling after the initial post-op swelling has gone down
- Persistent dry or red eyes

Parent Daily Checklist for Midface Distraction

1. Turn device in morning (as instructed by your doctor)

2. Check pins to see if loose

3. Check pin sites for signs of infection (redness, discharge, swelling)

4. Daily bath

5. Apply Vaseline to lips if dry

6. Give antibiotic pills (as instructed by your doctor)

7. Turn device in evening (as instructed by your doctor)

8. Call if problems / questions

9. Remember next clinic visit