Eden, age 10, was born with a submucous cleft palate. She has a passion for animals, especially dogs, and loves art.

John, age 6, was born with a submucous cleft palate. He dreams of joining the army when he grows up.
TYPES OF CLEFT PALATE

WHAT IS THE PALATE?
The roof of the mouth is called the palate. It has two parts. The hard palate is the stiff, front section of the roof of the mouth. The soft palate sits behind it. It is made of muscle and is covered by a mucous membrane. Behind the palate is the uvula. The uvula is the small muscle that dangles from the back of the mouth, between the tonsils.

The hard and soft palates play critical roles in eating, drinking, breathing and speech.

WHAT ARE THE TYPES OF CLEFT PALATE?
A cleft is a split, or opening. A cleft palate happens when parts of the roof of the mouth do not come together during early pregnancy.

A cleft palate can range in size from one person to the next. It can also vary in location. A complete cleft palate is a split in the entire roof of the mouth. An incomplete cleft palate is a split in part of the roof of the mouth. A bifid uvula is a split in the uvula.

A submucous cleft palate is an opening in the muscles of the soft palate, beneath a thin layer of tissue (mucous membrane.)

HOW IS A SUBMUCOUS CLEFT PALATE DIAGNOSED?
A submucous cleft palate may be hard to identify in some cases, even by experienced doctors. The cleft may be completely hidden behind a mucous membrane. The palate itself may look normal.

A submucous cleft palate is best diagnosed by looking at a combination of signs and symptoms, listed below. Any or all of these signs and symptoms contribute to the diagnosis of submucous cleft palate.

Signs of a submucous cleft palate
A person with a submucous cleft palate may have a normal looking palate. It is possible, though, that he or she may have any or all of the following signs:

- The uvula may be partially split or completely split. This is called a bifid uvula.
- The soft palate may have a blue-gray line down the center. It indicates that the muscles of the soft palate are separated.
- A cleft specialist may feel a separation of the muscles during a physical exam.
- A specialist may see or feel a V-shaped notch of tissue at the back of the hard palate or when the palate elevates. Sometimes this notch is visible, sometimes not.

Symptoms of a submucous cleft palate
Symptoms of a submucous palate may include:

- Nasal regurgitation. Liquid or food escapes through the nose while eating or drinking.
- Ear infections. The child has frequent ear infections caused by fluid in the ear.
• Hypernasal speech. The tone of voice sounds nasal because the palate muscles don’t work the way they should.

SUBMUCOUS CLEFTS AND SPEECH

MY CHILD’S SPEECH SOUNDS NASAL. WHAT DO WE DO NEXT?
A submucous cleft palate can cause problems with speech. A child born with a submucous cleft should be seen by a Speech-Language Pathologist (SLP) on his or her cleft team. The SLP on the team understands the special problems caused by a cleft palate. He or she can tell if a child’s speech problems are caused by the submucous cleft or by other factors.

WHAT IS VPI?
Velopharyngeal Incompetence (or VPI, sometimes called velopharyngeal insufficiency) is a common speech problem related to a submucous cleft palate. A child born with a submucous cleft may have problems with the muscles in the back of the soft palate. The muscles may not seal against the back of the throat the way they should. This can cause air to escape through the nose during speech.

A child with VPI may have a nasal sounding voice called hypernasality. The child may also have a hard time making hard consonant sounds.

WHAT ARE THE TESTS FOR VPI?
A Speech-Language Pathologist may recommend tests for VPI. A videofluoroscopy study is a moving picture of the palate and throat muscles during speech. For a nasoendoscopy, the SLP and/or a team surgeon uses a tiny camera to view the palate and throat during speech.

CARE AND TREATMENT

WILL MY CHILD NEED SURGERY?
A child born with a submucous cleft palate may or may not need surgery. The only reason to operate on a submucous cleft is to improve speech. If there are no problems with speech, surgery is not needed. If a child has hypernasality (a nasal sounding voice), surgery is usually needed to correct it. If the child has very mild hypernasality, it is possible that intensive speech therapy, alone, will help. This is rare.

The cleft team can’t know whether a child needs surgery for a submucous cleft palate until he/she starts to speak. When a child starts trying to make oral pressure consonant sounds like p, b, t, and d, the Speech-Language Pathologist on the team will do a speech evaluation. The SLP will find out if the child has hypernasality or if air leaks during speech. The SLP can also tell if a speech problem is caused by a physical issue or a learned issue. Families usually find out about surgery when a child is two or three years old.

The most common operation for a submucous cleft is called palatoplasty. For this procedure, the surgeon moves the muscles in the soft palate to close the hole. This allows the muscles to function more normally. There are different types of palatoplasties. Your doctor will tell you which one is best for your child.
WHAT OTHER OPTIONS EXIST TO IMPROVE SPEECH?
Surgery is not possible for some people because of other medical conditions or other reasons. Instead, a team may recommend an appliance called an obturator. An obturator looks like a retainer. It closes off the space behind the soft palate, for more normal sounding speech.

An obturator is custom-made by a dental specialist called a prosthodontist. It can be removed for cleaning or sleeping. An obturator usually needs to be replaced as a child grows.

WILL MY CHILD NEED SPEECH THERAPY?
Speech therapy helps a person move the mouth, lips and tongue correctly. There are several reasons why a person might need speech therapy. Many children born with a submucous cleft palate develop unusual speech habits if their palate is not working the way it should. Speech therapy helps correct those habits. A child might also need speech therapy after surgery or after getting an obturator. Speech therapy helps a child learn to produce sounds correctly, once the palate is working the way it should.

During speech therapy, a child should have speech evaluations to measure progress. Learned problems can be solved with speech therapy. Physical problems may require surgery. If speech still sounds nasal, the team may recommend another operation. This is rare.

DOES FLUID IN THE EARS HURT MY CHILD’S HEARING?
The space in the middle ear should be filled with air. In normal conditions, the Eustachian tube drains fluid and keeps the space dry. A submucous cleft palate can block the Eustachian tube. This can cause fluid to build up in the middle ear. Fluid can lead to ear infections and temporary hearing loss.

Children born with a submucous cleft palate should have regular ear check-ups with their doctor and hearing tests with an audiologist. If a child has fluid problems that last for three months, he or she should see an otolaryngologist (or, ENT.) An ENT is a surgeon who specializes in the ear, nose and throat. Ear fluid that lasts for more than three months can lead to problems with the eardrum and ear bones. It can also lead to hearing loss that may become permanent.

A child’s ENT may recommend tiny implants called pressure equalization tubes (sometimes called PE tubes, or ear tubes). Ear tubes allow the fluid in the ear to drain. Once the fluid has drained, the chance of infection goes down, and the child can hear better. Tubes are placed into the eardrum with a short surgical procedure. They usually stay in place for about a year.

Unfortunately, surgery for a submucous cleft palate only partly helps with ear fluid. A child born with a submucous cleft needs to have ongoing care with an ENT.

CLEFT PALATE-CRANIOFACIAL TREATMENT TEAMS

WHAT IS A CLEFT PALATE-CRANIOFACIAL TEAM?
A child born with a submucous cleft palate (of any type of cleft palate) needs to be treated by a cleft palate-craniofacial team. A cleft palate-craniofacial team is a group of specialists who work together. They coordinate a child’s care over the long-term. The doctors and specialists on the team work with a child and his or her parents to design a personal treatment plan. This leads to the best possible outcomes.

HOW DO I FIND A TEAM?
Treatment teams can be found in every state in the U.S. and elsewhere in world. To find a team in your area, visit the website of the American Cleft Palate-Craniofacial Association, www.acpa-cpf.org. Or, call 800.24.CLEFT (800.242.5338).

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