THE IMPACTS OF FOP ON HEARING, SPEECH AND SWALLOWING

Some individuals living with FOP share that complications from new bone growth and swelling in or around the ear, jaw and tongue are among the most significant challenges they face as FOP progresses. These changes can affect the individual's ability to swallow, speak clearly and hear. Understanding how FOP impacts these areas and taking proactive steps with specialists such as audiologists, laryngologists and speech-language pathologists can help individuals manage symptoms and improve quality of life.

HEARING AND FOP

The reported prevalence of hearing loss among individuals with FOP varies across studies. One study reported a prevalence of 5% in individuals under 18 years of age (She et al., 2020), while another found that 52% of survey respondents with a mean age of 25 years experienced hearing loss (Levy et al., 1999).

Cause of Hearing Loss

- Hearing loss is most likely to occur due to ossification of the middle ear structures.
- Conductive hearing loss, like that experienced in FOP, should improve with external amplification (such as hearing aids).

What Steps Should be Taken

- **Regular hearing evaluations should be done by an audiologist at least once a year**. If any hearing loss is detected, frequency of screenings should be increased based on conversations with an evaluating audiologist.
  - School screenings and primary care office checks are not sensitive enough as they only measure hearing on a simple pass/fail scale. These tests can miss the gradual, progressive hearing loss common in FOP. Regular evaluations by an audiologist are essential, as they provide detailed measurements that can detect even small changes over time.

SPEECH AND FOP

Speech can be impacted by FOP progression in one of three ways:

- **Respiratory restrictions:** Lung health can significantly impact the volume of one's speech, making it more difficult to understand the individual. For further resources and steps to take to protect one's respiratory health, visit our **FOP and Lung Health** page at **ifopa.org/lung_health**
- **Ossification (i.e. bone growth) of jaw muscles:** Reduced mouth opening can impact the ability to use one's lips properly to form words and also results in decreased volume of speech, making it more difficult for others to hear or understand the individual.

» **Ossification of the muscles around the tongue:** While the tongue is one muscle that does not ossify, the structures around the mouth and at the base of the tongue can experience bone growth. Reduced tongue mobility makes clear articulation a significant challenge, impacting the ability of others to understand an individual's speech.

A **speech-language pathologist (SLP)**, is a healthcare professional who assesses, diagnoses and treats communication issues in people of all ages, including speech and language issues and swallowing disorders. Educating specialists participate in an individual with FOP's care is critical. Referring them to the FOP Treatment Guidelines (found at iccfop.org/guidelines), Section 5-24 Submandibular Flare-ups in FOP, is a helpful reference point to start with.

SWALLOWING AND FOP

Swallowing can be impacted by FOP progression in two ways:

» **Ossification (i.e. bone growth) of the muscles around the tongue, jaw and neck regions:** This can impact the ability to open the mouth fully, chew and safely move solids and liquids to the esophagus.
» **Submandibular swelling (the area located under the lower jawbone):** This can impact the ability to push solids and liquids back to the esophagus in order to safely swallow and fully pass through the swallowing mechanism.

Any of these symptoms places an individual **at increased risk for aspiration (i.e. food or liquid going down the wrong pipe), compromised respiratory health and weight loss.** Working with a laryngologist or speech-language pathologist is key to receiving optimal care through the following services:

» A **modified barium swallow study/video fluoroscopy swallow study** (an active video x-ray of what food looks like going down into the esophagus) is critical in receiving a baseline of swallow function and determining if a swallowing disorder is present.
» Potential **diet modifications** that can be made or are necessary
» **Safe swallowing techniques** and precautions

It's important to see an Ear, Nose and Throat (ENT) specialist who is open to reading the FOP Treatment Guidelines, Section 5-25 Swallowing and FOP. They should also be willing to connect with FOP specialists and, if needed, anesthesia experts. In some cases, people with FOP may need to work with a gastroenterologist and use a feeding tube to ensure the person still gets enough nutrition and energy to continue daily activities.

REFERENCES

» She, D., Li, R., Fang, P., Zong, G., Xue, Y., & Zhang, K. (2020). Serum osteocalcin level is associated with the mortality in Chinese patients with fibrodysplasia ossificans progressiva aged ≤18 years at diagnosis. BMC Musculoskeletal Disorders, 21(1), 152. https://doi.org/10.1186/s12891-020-3170-3
» Levy, C. E., Lash, A. T., Janoff, H. B., & Kaplan, F. S. (1999). Conductive hearing loss in individuals with fibrodysplasia ossificans progressiva. American Journal of Audiology, 8(1), 29–33. https://doi.org/10.1044/1059-0889(1999/011)

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ADDITIONAL RESOURCES

Access additional resources for navigating care related to hearing, speech and swallowing by visiting **ifopa.org/ent-and-fop**. These resources include links to the most current FOP Treatment Guidelines and videos of presentations on the topics by experts in the ENT and speech pathology field.