

AN INTRODUCTION TO **FOP ORAL HEALTH**

Managing risk of oral disease is essential for patients with FOP. Good oral health not only enhances our ability to speak, smile, eat, breathe and show our emotions through facial expressions, but it can also help minimize risks of inflammation, flare-ups and potentially invasive dental treatments that could exacerbate complications of FOP and have long-standing consequences. The following recommendations have been provided as general guidelines for individuals with FOP to use starting in early childhood and extending through adulthood. Prevention is the key. Adapting these guidelines as life long habits will give individuals with FOP the best chance at living a life free from oral disease, and increased enjoyment from an overall higher quality of life.

GUIDELINES

0 TO 3 years of age



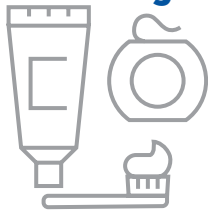
- » Visit a dentist by 1 year of age at the latest.
- » Clean gums with wet gauze after each breast or bottle feeding.
- » Brush teeth without toothpaste or use a small amount (size of a grain of rice) of NON-fluoride toothpaste without sweeteners. Only use fluoride toothpaste if living in an area where water is not fluoridated or if recommended by a dentist.
- » Brush 2 minutes, at least twice per day, and floss daily once teeth develop.
- » Minimize soft sugary foods (yogurt, for example, may contain excess sugar).
- » Fluoride varnish is suggested twice per year for children at high risk for oral disease.

3 TO 5 years of age



- » Continue general guidelines of brushing twice per day, flossing daily and minimizing sugar in the diet.
- » Visit a dental professional twice per year. If possible, visit every 3 months if your child is at risk for oral disease.
- » If your child can spit, start using a pea-sized amount of fluoride toothpaste. If they still swallow some toothpaste, stick with a smaller amount (size of a grain of rice).

OVER 5 years of age



- » Continue general guidelines of brushing 2 minutes, at least twice per day, and flossing daily. Most children need help to floss effectively until 10 or 11 years of age. If using floss aids, keep them clean after use on each tooth to avoid mouth contamination.
- » If your child is at risk for oral disease, a dental professional may recommend a high-dose fluoride toothpaste or rinse.
- » Continue to provide a diet low in sugar, choosing crunchy, healthy snacks to strengthen gums. Additionally, choose products containing xylitol (such as xylitol mints or gum) which is a healthier, natural sugar substitute made from birch trees that can help prevent tooth decay.
- » Monitor nasal or mouth breathing, snoring and teeth grinding. These put your child at increased risk for oral disease and require a visit to a dental specialist.
- » Care should be taken when opening your child's mouth to prevent overstretching of the jaw muscles which could trigger FOP flare-ups. Bi-annual professional visits should be sufficient, but visits every 3 months are best if there is risk of oral disease.
- » Saliva testing is highly recommended for patients with FOP. If a patient has inadequate saliva flow, habitual rinsing with water after eating is helpful. Saliva substitutes may also be helpful, such as MI Paste, gum containing xylitol and/or rinses.

ADULTS with jaw dysfunction or difficulty maintaining good oral hygiene



Adults should continue the general guidelines of brushing at least twice per day, flossing daily and limiting sugar in the diet. However, decreased mouth opening, jaw dysfunction or difficulty maintaining good oral hygiene puts an individual with FOP at high risk for oral disease and additional guidelines must be implemented. A dental professional should be seen at least every 3 months. The following recommendations should be discussed with your professional to determine the right combination for your individual needs:

- » High-dose fluoride toothpaste
- » Saliva testing and appropriate intervention based on results
- » Silver Diamine fluoride 38% application on any beginning lesion (cavity)
- » Fluoride and xylitol rinses, fluoride varnishes
- » Use of chlorhexidine rinses or varnish
- » Brushing and flossing aids – electric toothbrushes with small heads, water pics and floss wands are examples
- » MI Paste (topical tooth cream that replenishes tooth minerals, improves saliva flow and restores oral bacteria balance)

ADDITIONAL DENTAL AND ORAL HEALTH RESOURCES

Connect with FOP dental experts and view the full FOP Treatment Guidelines with dental recommendations at ifopa.org/oral_health_and_dentistry

Dental products and adaptive tool examples can be viewed at guidebook.ifopa.org