

Oral Cancer Screening for Individuals with Fanconi Anemia



WHY SCREENING MATTERS

Individuals with Fanconi anemia (FA) have a **500–1000x increased risk** of developing squamous cell carcinoma, especially in the **mouth, throat, and esophagus**. These cancers often develop by ages 30–35, but may appear earlier in individuals who have received a stem cell transplant.

Due to the DNA repair defect in FA, conventional treatments like **chemotherapy and radiation are often poorly tolerated**. Regular dental exams are a crucial component of identifying precancerous lesions before they become life-threatening.

Since FA patients are frequently diagnosed at late stages, **routine screenings** and **non-invasive brush biopsies** can significantly improve outcomes. **Early detection is essential** for survival.



SCREENING RECOMMENDATIONS

- **Ages 12+:** Minimum twice-yearly oral cancer screenings
- **Adults:** Ideally 3–4 screenings/year
- **If lesions are present:** At least 4 screenings/year, including brush biopsies
- **Document** oral changes with diagrams/photos
- **Ask patients:**
 - Are you enrolled in the NIH FA Cancer Screening Study?
 - Are you up to date with other specialist-recommended cancer screenings?



BRUSH BIOPSY: A SIMPLE, LIFE-SAVING TOOL

A brush biopsy is a **quick, non-invasive** way to assess **suspicious lesions** (e.g., leukoplakia, erythroplakia). While often benign, these can turn malignant in FA.

- Enables early monitoring/intervention
- If results are uncertain or positive, refer for a scalpel biopsy
- Can be coordinated through the NIH FA Cancer Screening Study

QUICK RESOURCES WITH MORE INFORMATION



FA Clinical Care Guidelines
Chapter 6: Oral Health Care



Add-On Oral Screening
Information for Providers



NIH CANCER SCREENING STUDY

National Institutes of Health, Bethesda, MD

Ages 12+ (and 8–12 with symptoms) can enroll for:

- Oral exams & brush biopsies
- Screening for esophageal, gynecological, and anal cancers
- Access to cytology and DNA cytometry tools
- NIH can provide biopsy kits and collaborate with local dentists



*Video for Dentists
(QR code left)*



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🔗 <https://marrowfailure.cancer.gov/fanconi-anemia/>



INTERNATIONAL FANCONI ANEMIA REGISTRY (IFAR)

The Rockefeller University, New York, NY

Open to all individuals with FA. IFAR collects tissue and data to support cancer research in FA.

- Coordinates studies of premalignant and malignant lesions
- Please encourage enrollment and see the “Oral Cancer Research in FA” flyer (left)



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EMPOWER PATIENTS TO STAY PROACTIVE WITH FA EXAM APP

As a dentist, you're a key part of the FA care team. Encourage patients to use the FAexam app to take charge of their oral health. Download in the Apple or Android store.

Designed for individuals with FA to track oral health and monitor changes:

- Self-exam tutorials
- Oral image/documentation storage
- Symptom and mood tracking
- Appointment reminders
- Share reports with care team



NEED EXPERT INPUT? REFER TO THE VIRTUAL TUMOR BOARD (VTB)

The Fanconi Cancer Foundation facilitates expert case reviews through our Virtual Tumor Board. FA specialists from around the world collaborate to support complex care decisions.

To request a review, contact:

✉ communitysupport@fanconi.org | 📞 541-687-4658

QUESTIONS OR NEED SUPPORT?

The Fanconi Cancer Foundation offers:

- FA-knowledgeable peer and clinical referrals
- Patient and family support services
- Provider guidance

📞 1-888-326-2664 | 541-687-4658

✉ communitysupport@fanconi.org

🌐 fanconi.org