

# ORAL SELF-EXAMINATION FOR FA INDIVIDUALS



Deutsche Fanconi-Anämie-Hilfe e.V.



FANCONI ANEMIA RESEARCH FUND  
Advancing Research. Supporting Families.

[www.fanconi.de/icare](http://www.fanconi.de/icare)

## 1 Instructions

Individuals with FA often have visible spots in their mouths that come and go and are nothing to worry about. In rare cases, these spots (called lesions) are premalignant or already cancerous. Consistent and thorough observation can lead to early detection of important changes that can be monitored and/or treated effectively. Therefore, in addition to regular visits to the dentist and ENT (Ear, Nose and Throat specialist), monthly self-examination or examination by a family member with documentation is recommended.

## PROCEDURE OF AN ORAL SELF-EXAMINATION

### 1 UPPER JAW

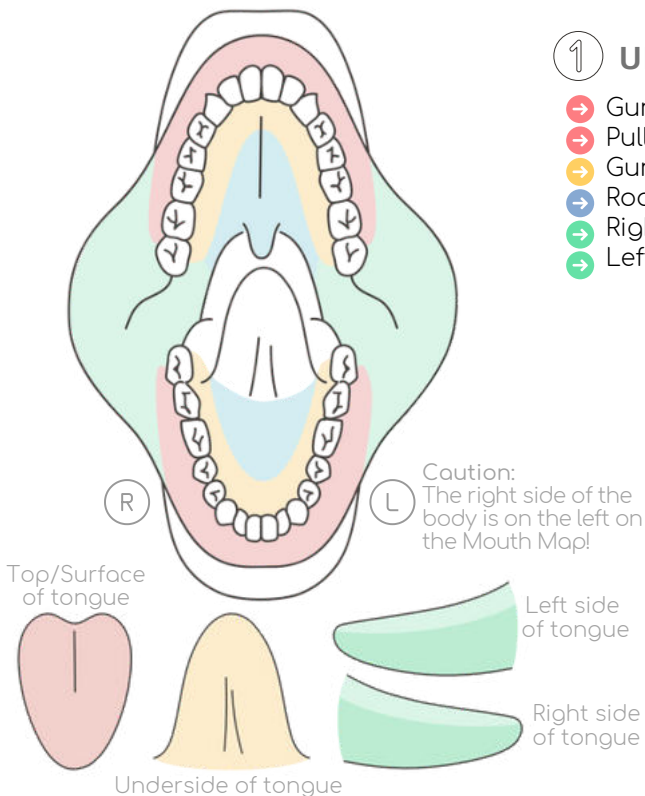
- Gums around the outside of the teeth
- Pull upper lip upwards as far as possible
- Gums inside of the upper jaw, by upper teeth
- Roof of the mouth, including back towards the throat
- Right cheek (pulling cheek out to view as far back as possible)
- Left cheek (pulling cheek out to view as far back as possible)

### 2 LOWER JAW

- Gums, around the outside of the teeth
- Pull lower lip out and down as far as possible
- Gums inside the lower jaw, by lower teeth
- Floor of the lower jaw, where tongue rests (lift tongue)

### 3 TONGUE

- Surface of tongue as far back as possible
- Underside and tip of the tongue Complete right
- side of the tongue
- Complete left side of the tongue



## HOW TO EXAM?

- Examine systematically e.g. always from right to left and top to bottom
- Illuminate the areas as much as possible e.g. use a headlamp, cell phone, flashlight or use an illuminated magnifying mirror
- Documentation: Use the mouth map & take pictures (explanations on the next pages)

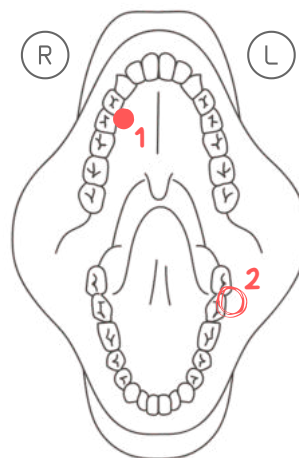
## WHAT SHOULD YOU LOOK FOR?

Note down all visible spots that look different or just don't "look right". Find examples of lesions at: [www.fanconi.de/icare\\_en](http://www.fanconi.de/icare_en)

## WHAT TO NOTE DOWN

Are these new spots? How long have you noticed them? What changes do you see? What colors are the spots? What size and texture? Do they hurt or bleed? Can you imagine a reason for them?

## EXAMPLE OF DOCUMENTATION USING A MOUTH MAP



Mark, number, describe and take a picture!

Date:

02/04/2022

Number 1:

has been there since 2021, no changes

Number 2:

About there a week, slightly sore and a bit painful, white-reddish, about 0,2 inch

Download the mouth map (self-examination documentation sheet) at: [www.fanconi.de/icare\\_en](http://www.fanconi.de/icare_en)

## ALL INFORMATION ON: [WWW.FANCONI.DE/ICARE](http://WWW.FANCONI.DE/ICARE)

[christine.krieg@fanconi.de](mailto:christine.krieg@fanconi.de)  
[velleuer@uni-duesseldorf.de](mailto:velleuer@uni-duesseldorf.de)

## EXAMINATION SCHEDULE

- Semi-annual check-up at dentist if the oral mucosa is inconspicuous / In case of abnormalities check-up once per quarter
- perform oral self-examination once per month

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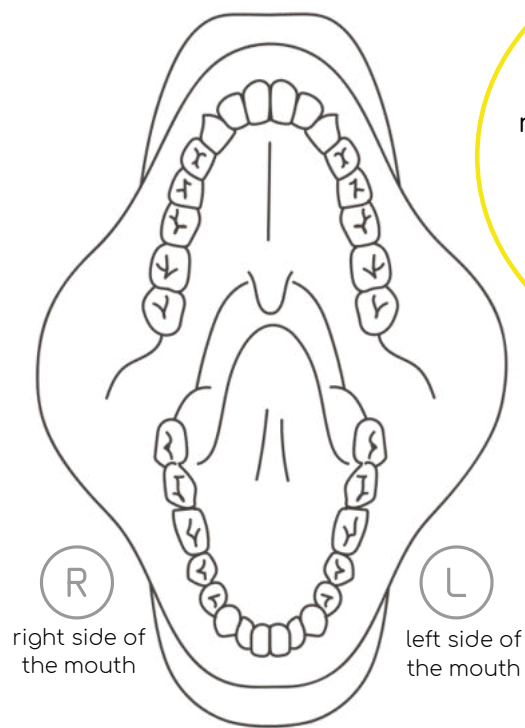
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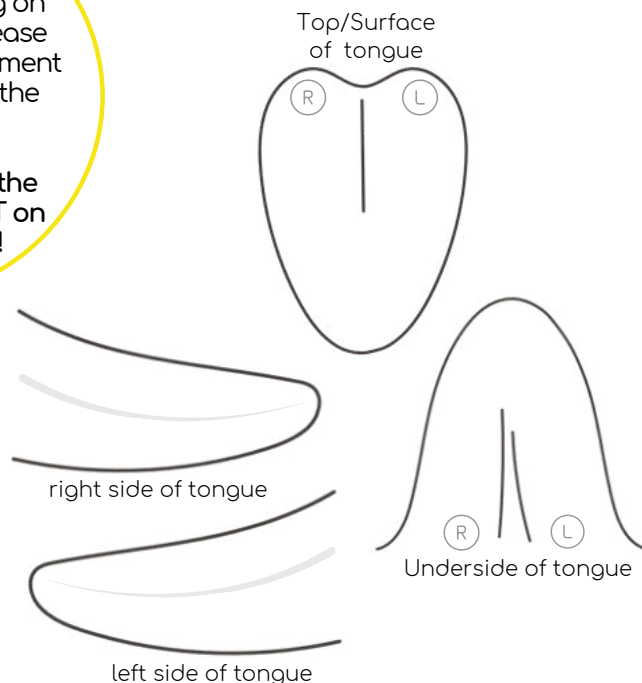
## 2 Mouth Map Documentation



### ATTENTION!

When documenting on the Mouth Map, please make sure you document the correct side of the body!

The **RIGHT** side of the body is on the **LEFT** on the Mouth Map!



### DOCUMENTATION OF VISIBLE SPOTS

- 1 Mark each spot on the Mouth Map being careful to document the correct location (left/right side)
- 2 Number each spot and describe it
- 3 Take a picture with good lighting (see explanations on the next sheet)

Date

Number 1: New or known? Changes? Color? Size & texture? Pain or bleeding? Explanation?

Number 2: New or known? Changes? Color? Size & texture? Pain or bleeding? Explanation?

Number 3: New or known? Changes? Color? Size & texture? Pain or bleeding? Explanation?

**IF VISIBLE SPOTS HAVE NOT DISAPPEARED AFTER 2-3 WEEKS, THEY MUST BE EXAMINED BY A DOCTOR**

To document additional spots, please use the reverse side.

**NOTE DOWN ALL VISIBLE SPOTS + TAKE A PICTURE!**



**Upper jaw:** outside gum (pull up upper lip to max) - inside gum - palate - right + left cheek  
**Lower jaw:** outside gum (pull down bottom lip to max) - inside gum - floor of mouth  
**Tongue:** top/surface - right + left side - underside and tip of tongue

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## 3 Photographic Documentation

### DOCUMENTATION

Optimal documentation includes two important steps: 1. Note visible spots on the Mouth Map and describe them as accurately as possible. 2. Take clear, well-lit photos of each spot.

### TIPS & TRICKS FOR TAKING GOOD PHOTOS

- Photos taken by another person are much more effective than selfies (pay attention to right-left challenge).
- Always use good lighting (e.g. light of a window, flashlight...) and good focus.
- Attempt to reduce light reflections (shine) on the spot.
- Take several photos from different distances and angles. Include surrounding structures for reference, and take one additional picture as close as possible, with good focus (see below).

### EXAMPLES

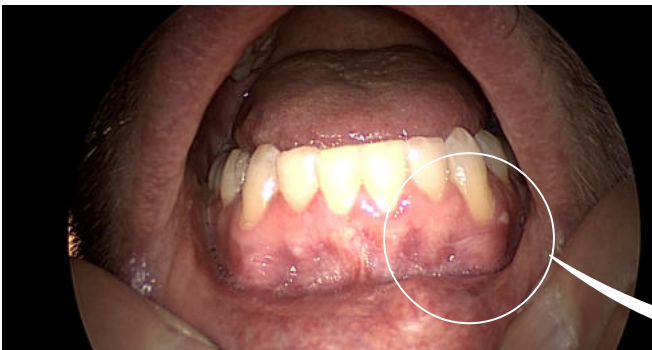


Photo 1: You can clearly see the relationship of the visible spot to the left lower jaw (surrounding structure for reference).



Photo 1: You can clearly see where exactly the visible spot is located in the mouth (surrounding structure for reference).

### PHOTODOCUMENTATION IS IMPORTANT!

It is easy to forget what a visible spot (lesion) looked like just two weeks earlier. The photos help to observe and record the exact course of a lesion (improvement, worsening, or remaining the same).

This evolution of the lesion is very important!

### ATTENTION: RIGHT & LEFT SIDE VARIES IN DIFFERENT CAMERAS

The reversal of the sides is a challenge for accurate documentation. Different cameras yield different results:

Front camera (selfie): Right side of the body is mostly right when viewing images.

Back camera (main camera): Right side of the body becomes the left side when viewing the images.

IT'S VERY IMPORTANT THAT YOU NOTE THE VISIBLE SPOTS CORRECTLY IN THE GRAPHIC MOUTH MAP



Photo 2: You can see the spot in detail, it is sharp, properly exposed (not too dark, not too bright) and has no reflection.



Photo 2: You can see the spot in detail without reflection.

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## Examples of visible oral lesions

[www.fanconi.de/icare](http://www.fanconi.de/icare)

### EARLY DETECTION OF CHANGES IN THE ORAL CAVITY

Individuals with FA often have visible spots in their mouths that come and go and are nothing to worry about. In rare cases, these spots (called lesions) are premalignant or already cancerous. Consistent and thorough observation can lead to early detection of important changes that can be monitored and/or treated effectively.

Therefore, in addition to regular visits at the dentist and ENT (Ear, Nose and Throat specialist), monthly self-examination or examination by a family member with documentation is recommended.

### EXAMPLES OF LESIONS

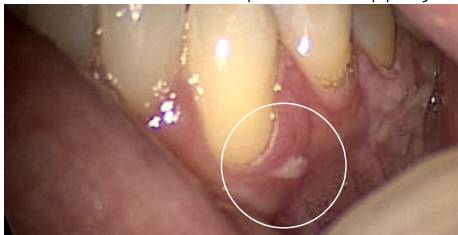
Clearly visible lesions **WITHOUT** cancer or precancerous cells (after clarification by a specialist!\*)



Pronounced white spot on the upper jaw



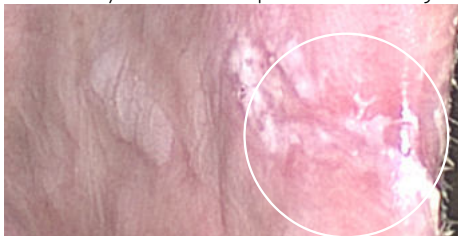
Slight redness and bright spots on the palate



Barely visible white spot on the lower jaw



Bright area on the lower jaw



White spots at the corner of the mouth

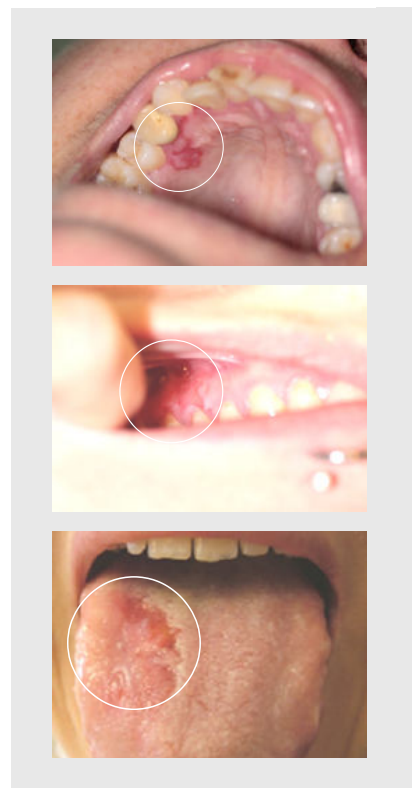


Small red-white spot on the side of the tongue

### WHAT ARE "VISIBLE SPOTS" (LESIONS)?

Self-examinations do not replace a regular visit with your treating physician. Nevertheless, it is very helpful to examine the oral cavity regularly yourself and look for visible spots. The pictures below show examples that look different from a normal mouth and they should be observed and documented in any case. Even if spots are smaller and not quite visible, they should be recorded. This allows a comparison over weeks and months, which is very important.

Lesions **WITH** cancer or precancerous cells



As soon as a spot is not only "whitish" but "white-red" or "clearly red" or "red-blooded", we advise immediate examination by a specialist.

**\*IMPORTANT:** If visible spots and areas have not disappeared after 2-3 weeks, they must be examined by a specialist!

### QUESTIONS TO ASK WHEN OBSERVING A SPOT

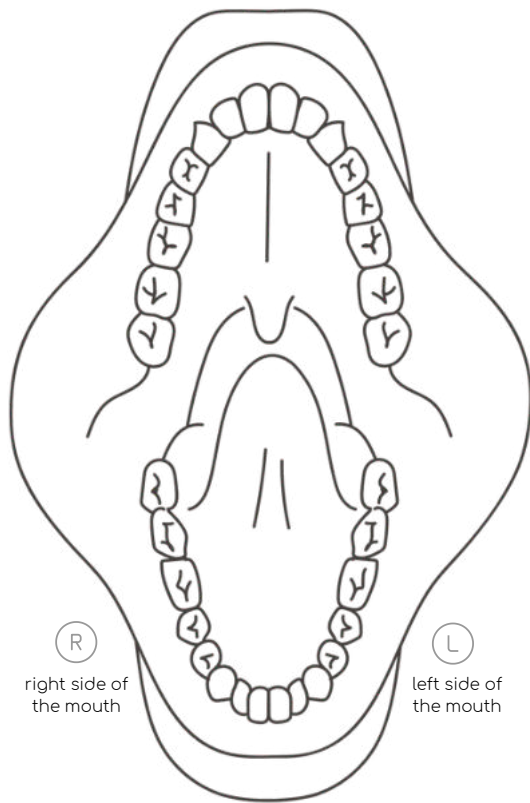
Is the spot new? How long has it been there? Are there possible reasons for it, such as a burn from hot food; a bite spot or injury from braces; infection? What changes do I see? What colors do the spots have? What size and texture do they have? Do they hurt or bleed? Note every detail.

**ALL INFORMATION ON:  
[WWW.FANCONI.DE/ICARE](http://WWW.FANCONI.DE/ICARE)**

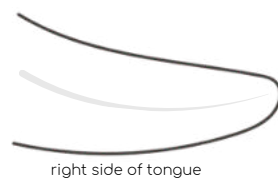
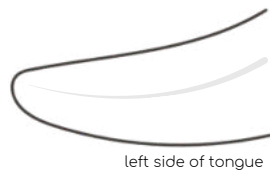
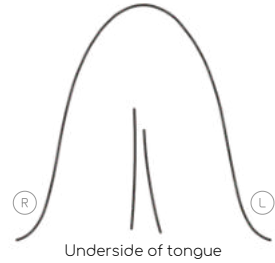
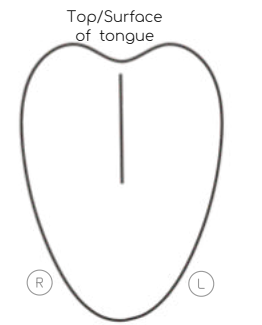
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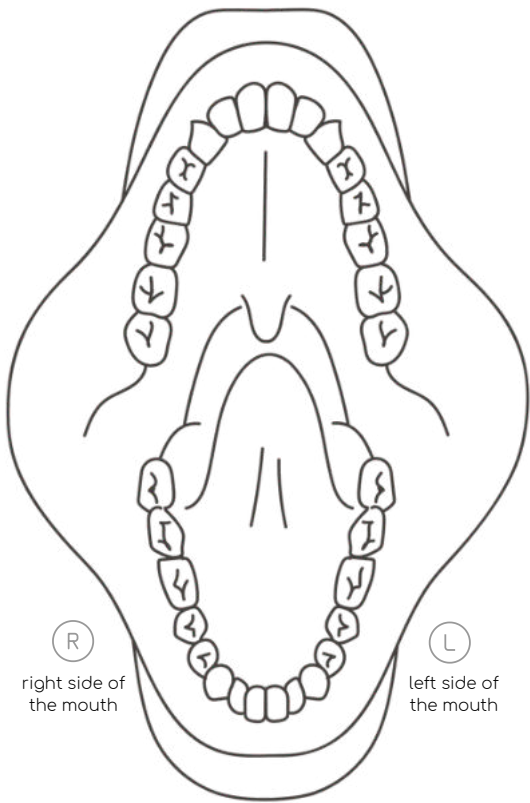


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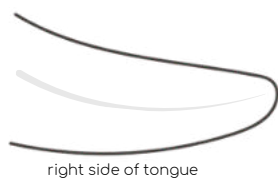
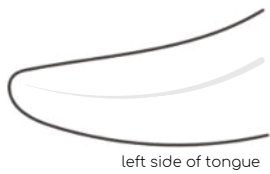
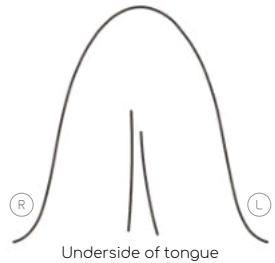
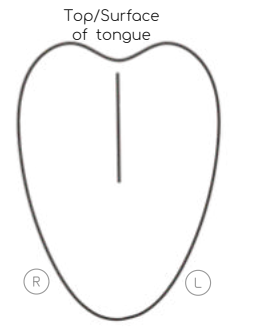
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Notes

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