

FA Meeting, Bordeaux, 2022

"Power 2 U"

New campaign to manage the
increased risk for oral cancer in FA

Eunike Velleuer & Christine Krieg



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We are part of the FA Cancer Consortium!



EARLY PREVENTION

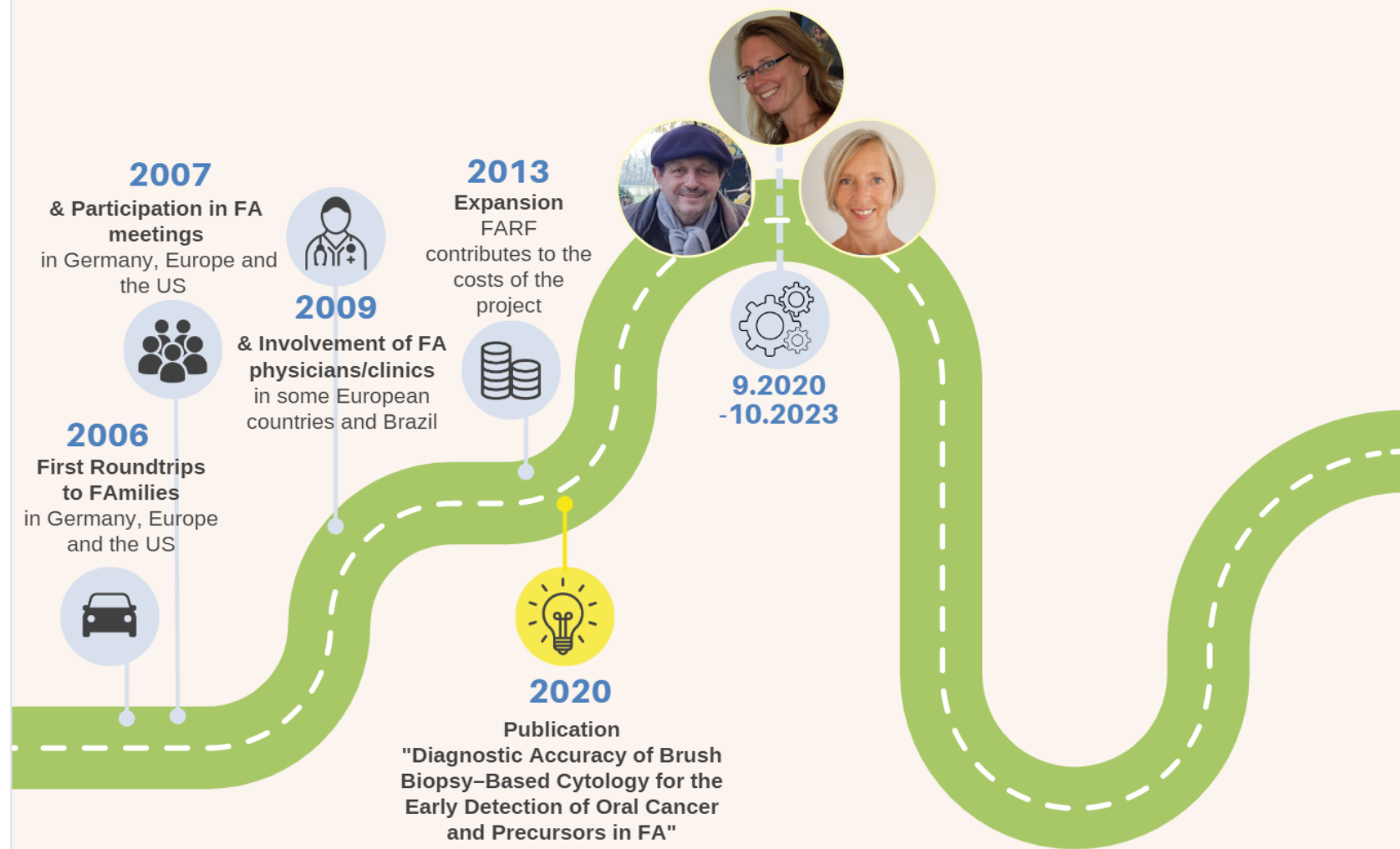
Dealing with the increased risk of oral cancer

How it all began...

Since 2009 project:

“Reducing the burden of squamous cell carcinoma in Fanconi anemia”

Prevention of oral cancer for Fanconi anemia patients



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Implementation & Empowerment

Reducing the burden of
Squamous cell carcinoma in Fanconi anemia

Implementation in
the field

Data analysis

Re-use material

Empowerment

PILLARS OF
THE PROJECT



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GOALS OF

IMPLEMENTATION &
EMPOWERMENT

= AWARENESS
OF ORAL LESIONS

Goal: Early detection

Prevention of oral cancer for Fanconi anemia patients

Awareness
of early lesions
which could lead to
oral cancer at
young age



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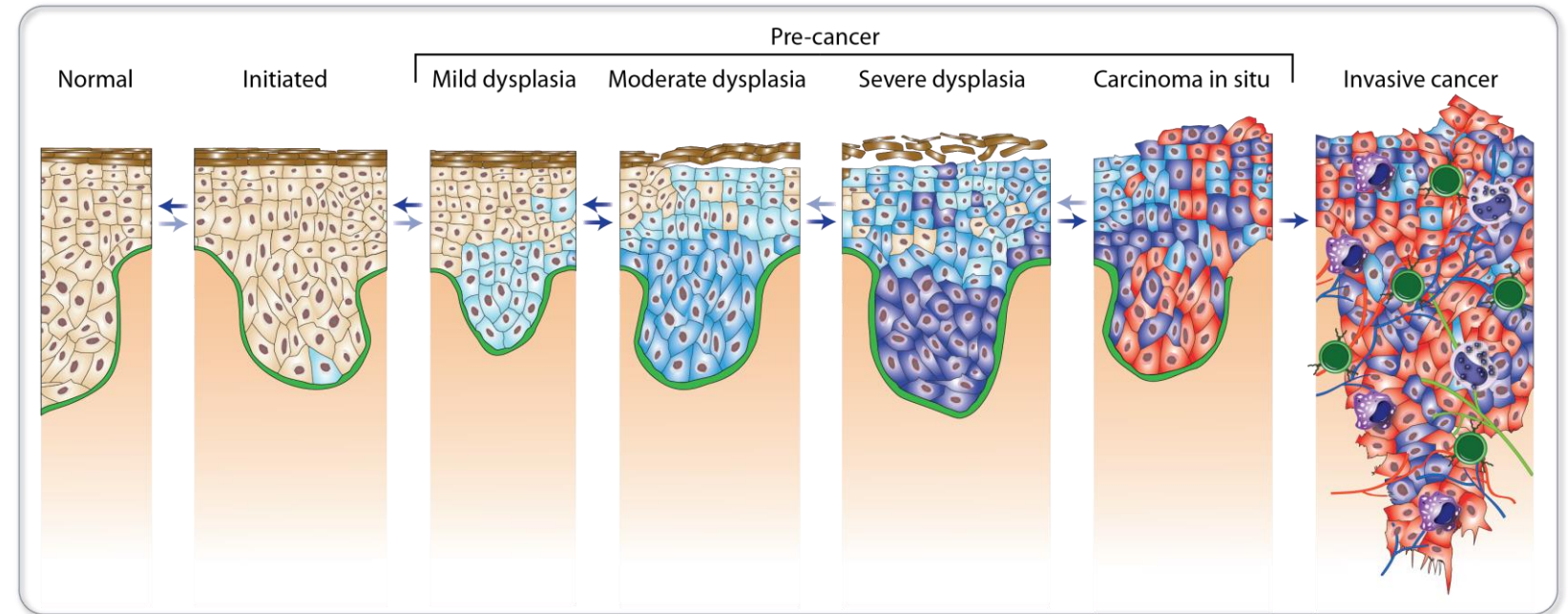
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CANCER & ORAL LESIONS



ORAL LESIONS

POINT OF NO RETURN

CANCER

PREVENTIVE SCREENING



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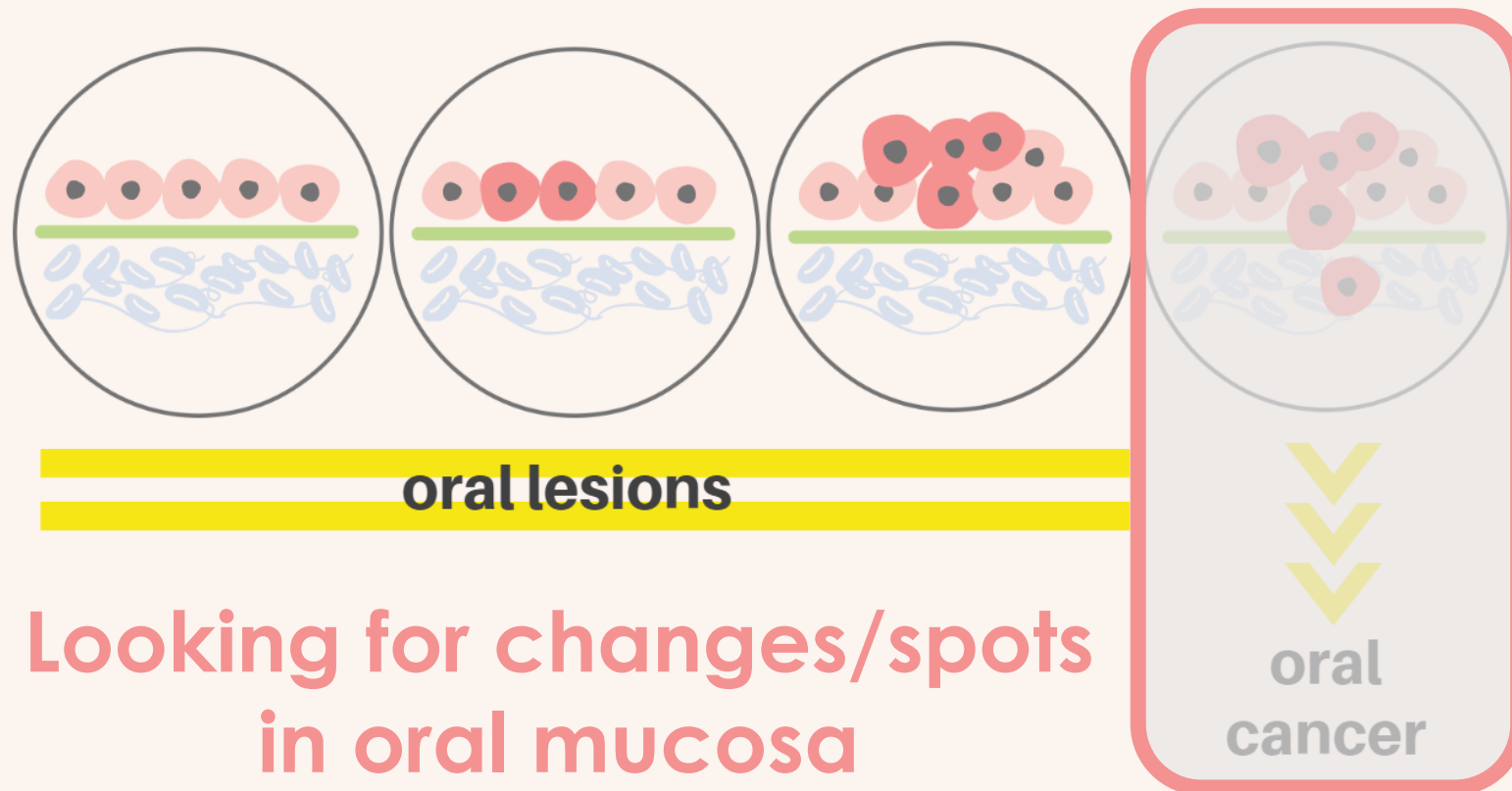
EARLY DETECTION
OF ORAL CANCER

= SCREENING FOR
ORAL LESIONS

PREVENTIVE
ORAL SCREENING=

Screening of oral lesions

Prevention of oral cancer for Fanconi anemia patients



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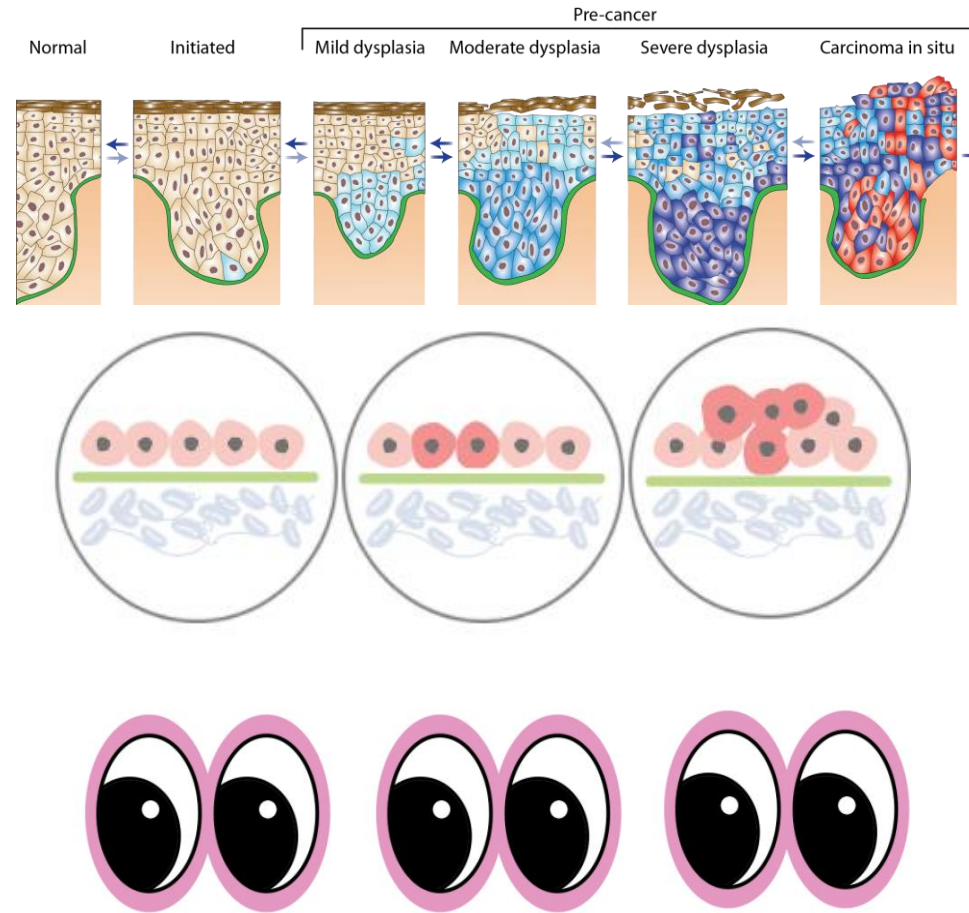
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PREVENTIVE SCREENING FOR ORAL LESIONS

= USAGE OF
VISEBILITY & TIME



FIELD OF PREVENTIVE SCREENING!



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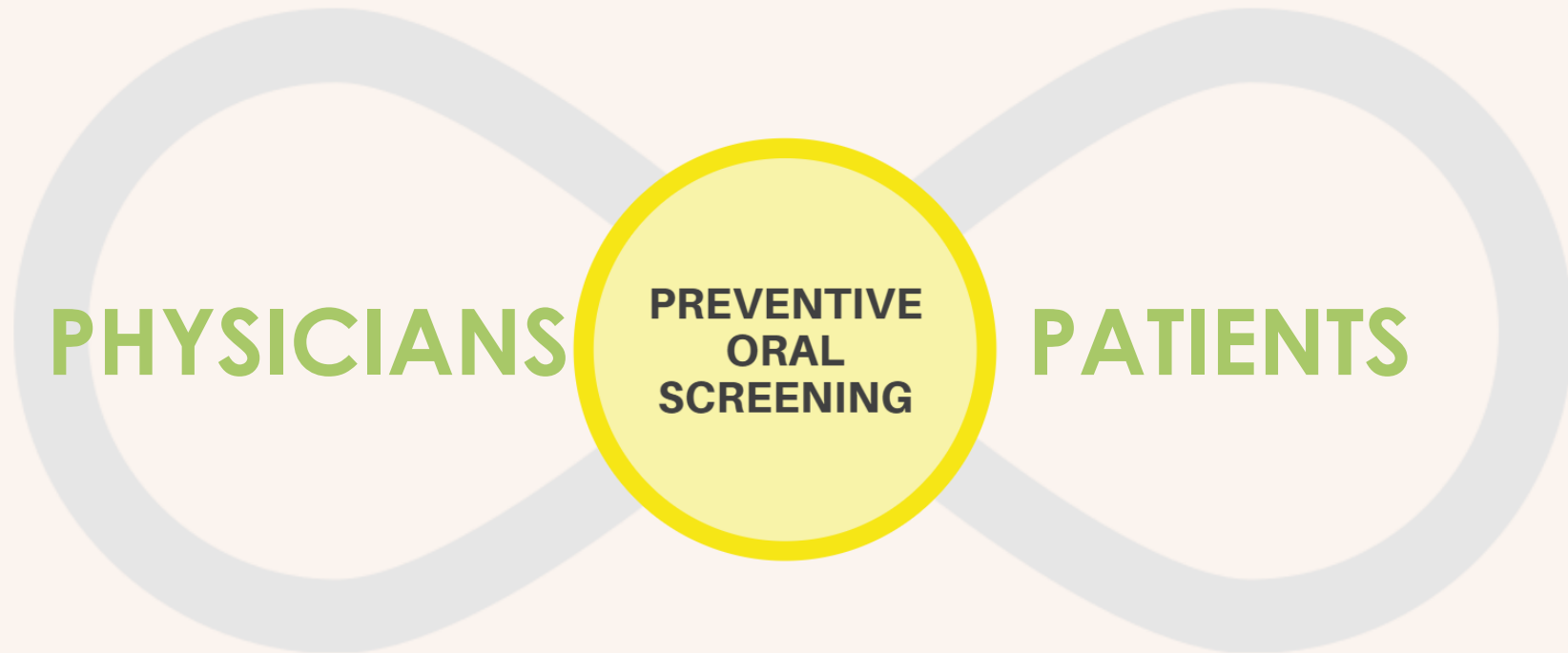
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PREVENTIVE ORAL SCREENING

TWO COMPLEMENTARY GROUPS

Infinity of screening
of preventive oral screening in Fanconi anemia patients



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THE RHYTHM OF PREVENTIVE ORAL SCREENINGS

YOUR MOUTH SELF-
EXAMINATION IS NOT
INTENDED TO REPLACE
YOUR PHYSICIAN!

Infinity of screening

of preventive oral screening in Fanconi anemia patients

2-4 times
per year



At doctors
office

Every
month



Self-
Examination

&



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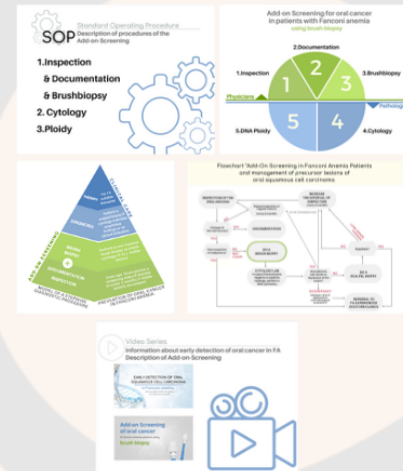
MATERIALS & SUPPORT FOR PREVENTIVE ORAL SCREENING

FOR PATIENTS:
[FANCONI.DE/ICARE](https://fanconi.de/icare)

Material & Support for Screening

Preventive Screening of oral lesions in Fanconi anemia patients

Add-on Screening for clinicians



Info for clinicians:
fanconi.de/scc_en

Self- Screening for patients



Info for patients:
fanconi.de/icare

Information Education Training



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LEARN MOUTH SELF - EXAMINATION



TEACHING MATERIAL



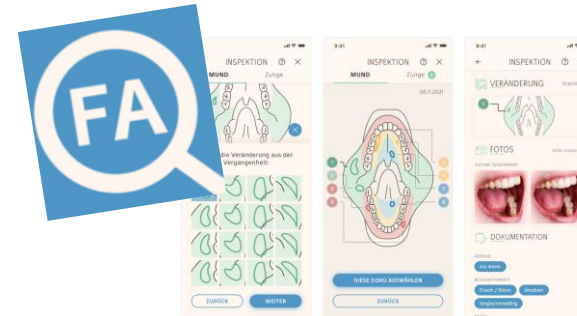
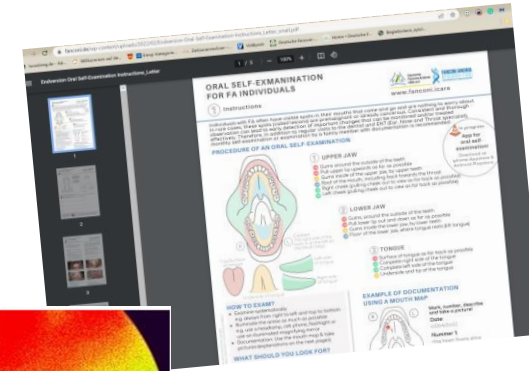
VIDEO



TRAINING



APP “FAexam”



DEVELOPMENT WITH
INTERNATIONAL
SUPPORT OF
FADULTS

THANK
YOU!!!



Development of material for self screening

Self-Screening
instructions
Groups from
Denmark,
Germany, US

Teaching-Videos
Group of Germans,
Danish & US-
Individuals

APP
Group of Germans,
Beta-Testing
pending

support of
40 individuals
with FA



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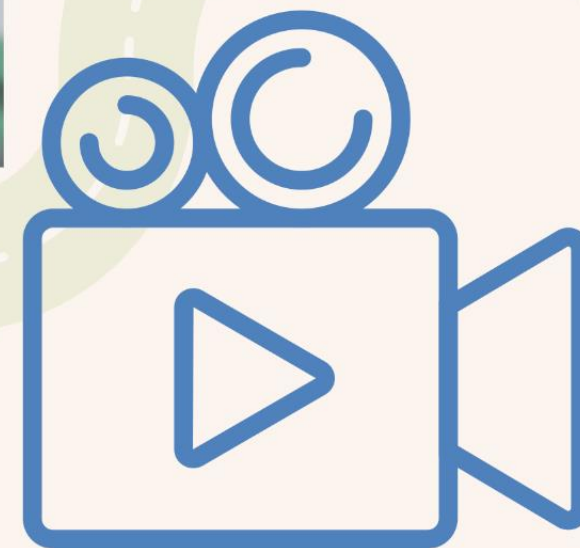
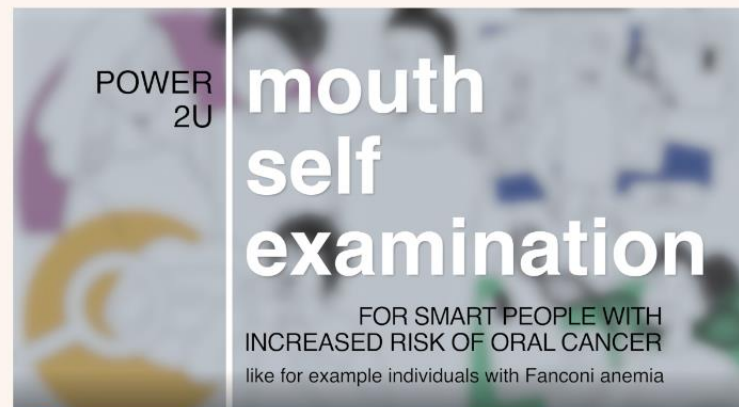
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POWER 2U TEACHING VIDEO

Material & Support for self screening

Preventive Screening of oral lesions in Fanconi anemia patients



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THE 2 STEPS OF SELF-EXAMINATION INSPECTION & DOCUMENTATION

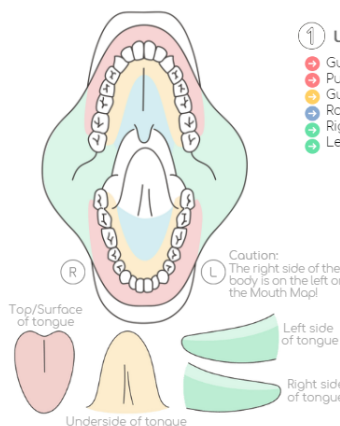
www.fanconi.de/icare

ORAL SELF-EXAMINATION FOR FA INDIVIDUALS

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)

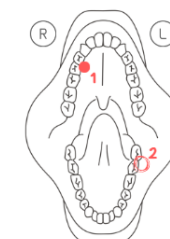
2 LOWER JAW

- 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

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

ALL INFORMATION ON:
WWW.FANCONI.DE/ICARE
christine.krieg@fanconi.de
veller@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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ORAL SELF-EXAMINATION FOR FA INDIVIDUALS

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. This evolution of the lesion is very important!

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 or good phone)
- Attempt to reduce light reflections (phone) 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 2: 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 few 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. From camera (selfie): Right side of the body is mostly on the left when viewing the image. From camera (phone): Right side of the body becomes the left side when viewing the image.

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



Photo 3: You can see the spot in detail, it is sharp, properly exposed (not too dark, not too bright) and has no reflection.



Photo 4: You can see the spot in detail without reflection.

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ORAL SELF-EXAMINATION FOR FA INDIVIDUALS

Examples of visible oral lesions

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 classification by a specialist)

Lesions WITH cancer or precancerous cells

As soon as a spot is not only "white" but "white-red" or "red-bleeding", an active immediate examination by a specialist

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

QUESTIONS TO ASK WHEN OBSERVING A SPOT

In the spot, 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.

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ORAL SELF-EXAMINATION FOR FA INDIVIDUALS

Examples of visible oral lesions

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 differ from a normal mouth and they should be observed and documented in any case. Even if spots are small and not quite visible, they should be recorded. The above is comparison over weeks and months, which is very important.

EXAMPLES OF LESIONS

Clearly visible lesions WITHOUT cancer or precancerous cells (after classification by a specialist)

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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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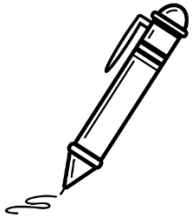


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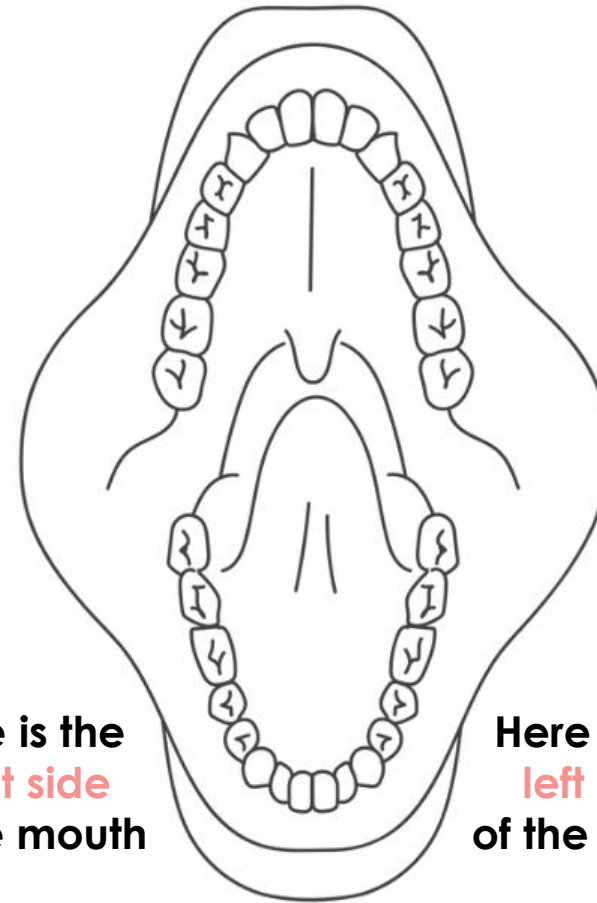
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ATTENTION MARKING IN MAP

Make sure you document
the correct side of the
body!

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



Here is the
right side
of the mouth

Here is the
left side
of the mouth



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ATTENTION TAKING PHOTOS



- ✓ Look for good light
- ✓ Sharp
- ✓ different distances & angles

✓ Let others help you!



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KEEP CALM

often visible spots (lesions) in FA
come & go, mostly nothing to worry about
many causes: injuries, bacterial, viral or fungal infections

Consistent and thorough observation
(+ monitoring)
= early detection of important changes
= early + effective treatment



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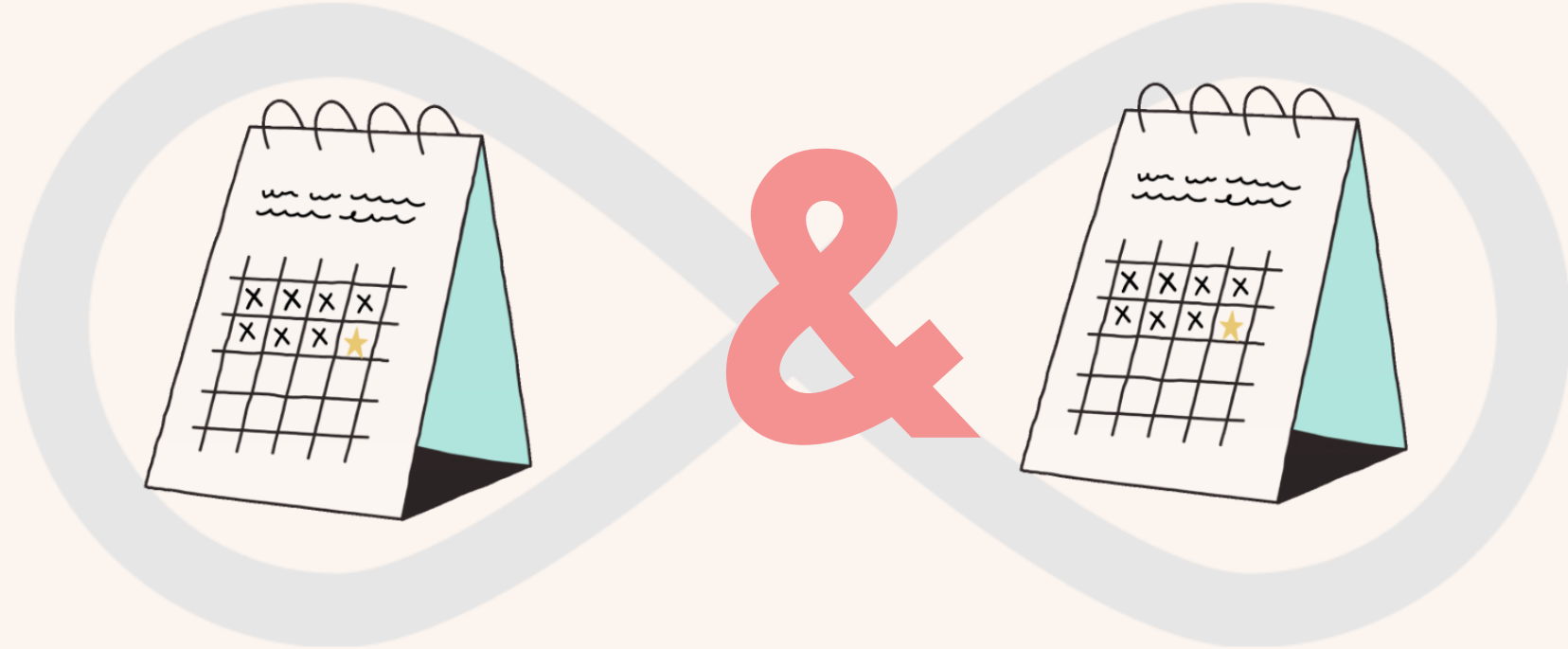
THE RHYTHM OF PREVENTIVE ORAL SCREENINGS

Doctors office
2-4x per year

&

Self-examination
1x per month

Infinity of screening of preventive oral screening in Fanconi anemia patients



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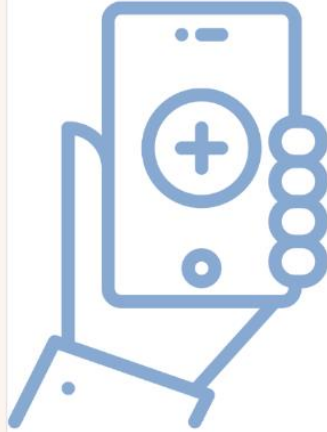
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FUTURE GOALS & NEXT STEPS

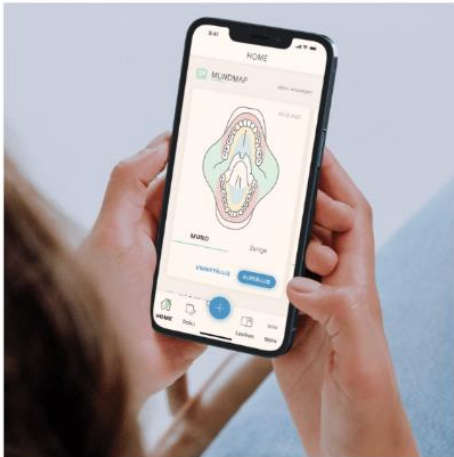
- **Beta-Testing APP**
- **Teaching & Training**
- **Development of new Health- & Lifestyle-Questionnaire**

Material & Support for self screening

self examination & documentation for patients



App
Documentation of Screening
Reminder System
Overview & Export of all documented lesions
Comparison of same lesion over time
Gateway to FA Information



Info for patients: fanconi.de/icare



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