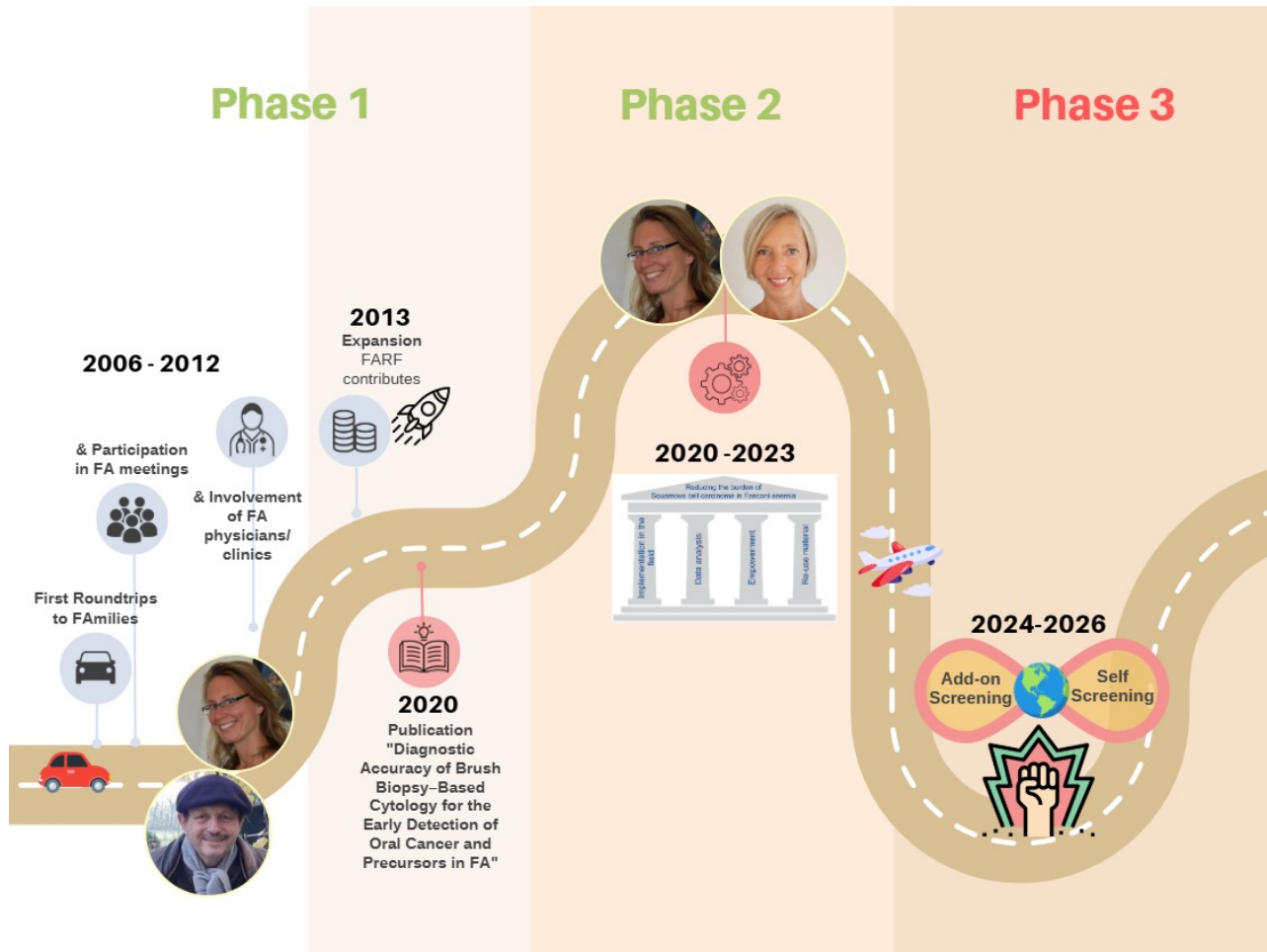


Add-on screening opportunities and self-empowerment strategies in FA

Dr. Eunike Velleuer-Carlberg
Krefeld and Düsseldorf, Germany

Early prevention: Reducing the burden of SCC in FA



- **Higher Quality of Life**
- **Higher Life Expectancy**

Velleuer et al 2020

Goal: Early detection

Prevention of oral cancer for Fanconi anemia patients

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

Add-on ORAL SCREENING

TWO COMPLEMENTARY GROUPS

Infinity of screening
of preventive oral screening in Fanconi anemia patients

PHYSICIANS

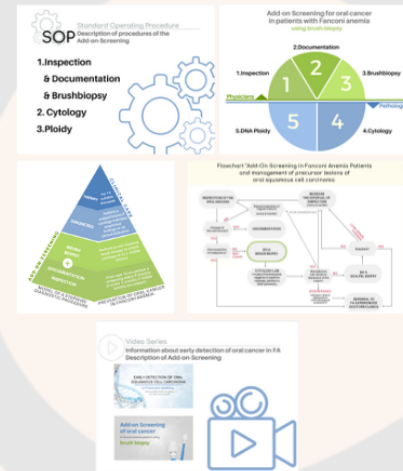
PREVENTIVE
ORAL
SCREENING

PATIENTS

MATERIALS & SUPPORT FOR PREVENTIVE ORAL SCREENING

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



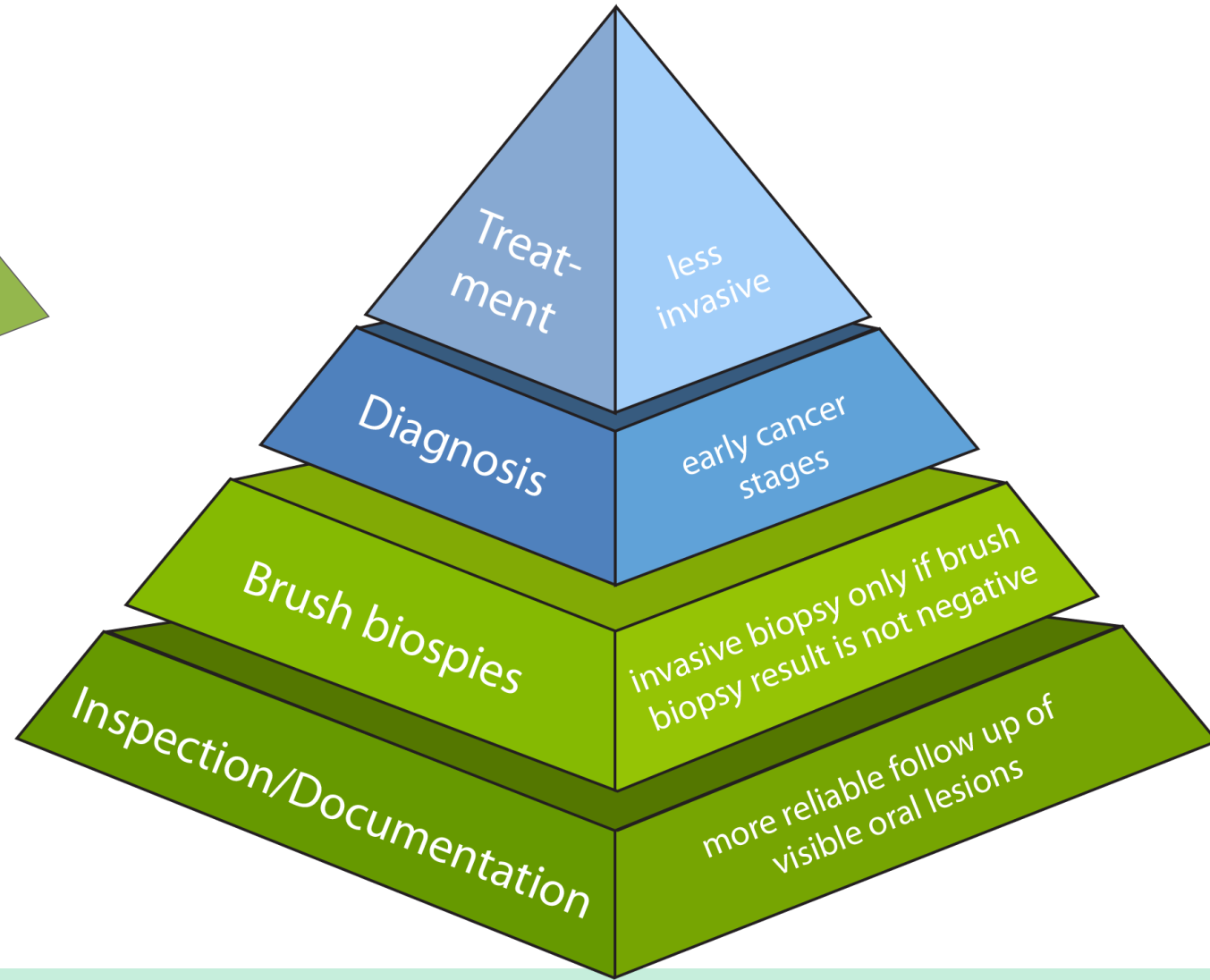
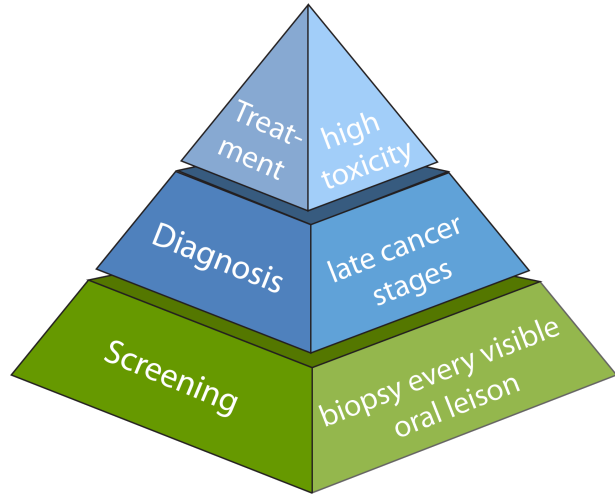
Info for patients:
fanconi.de/icare

Information Education Training

The hallmarks of cancer screening

- Accessibility to target population (different healthcare settings and affordability)
- Evidence-based
- Risk assessment (should take individual risk factors into account)
- High sensitivity and negative predictive value
- Non-invasiveness
- Benefit-risk balance
- Follow-up diagnostic procedures

What is the Add-on Screening

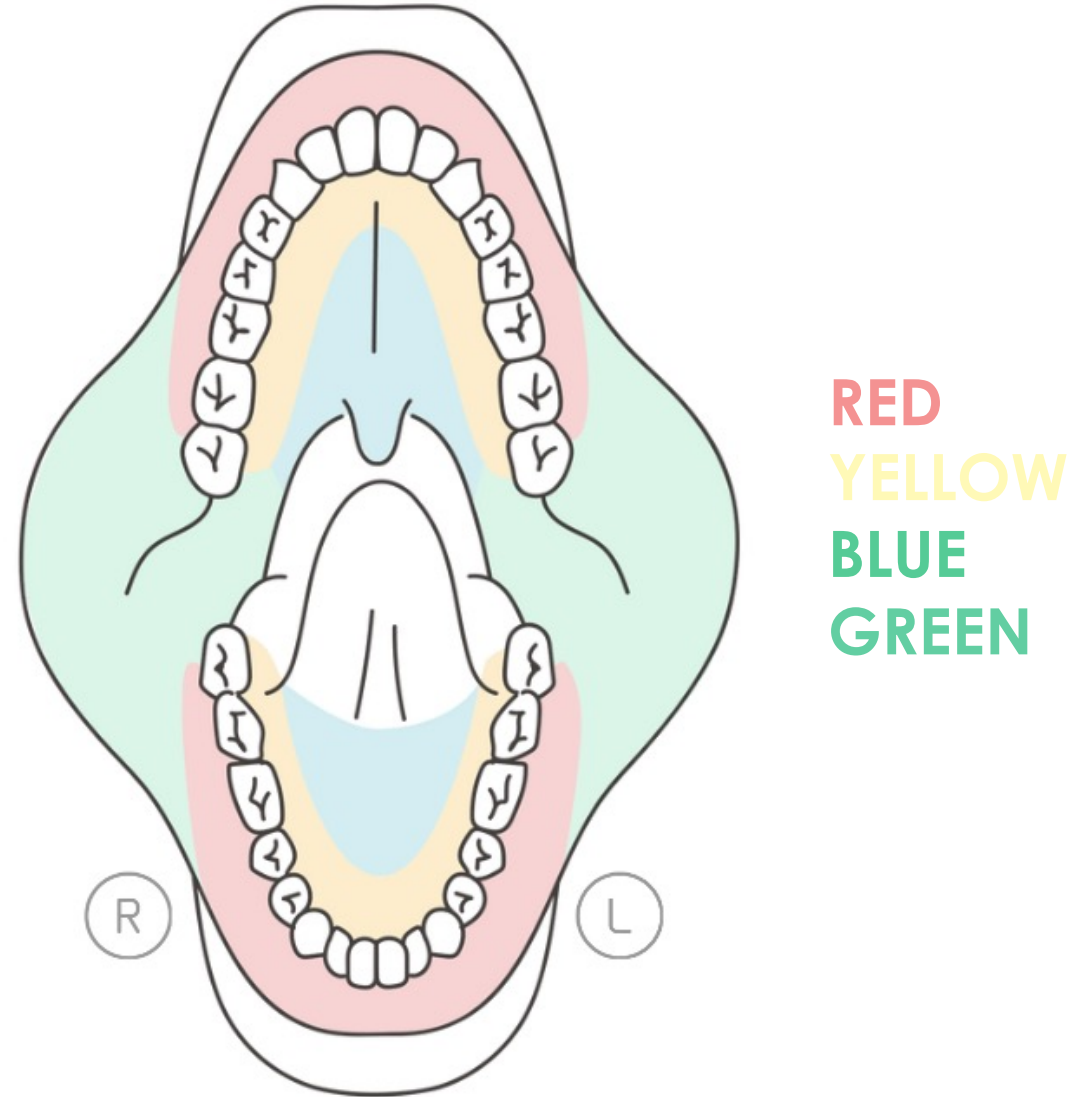


Add-on preventive screening for oral cancer in patients with Fanconi anemia using brush-biopsy



Inspection

- Search for lesions!
- Only what you detect, can be documented and brushed!

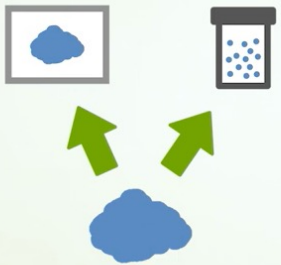


Documentation



Documentation

Improved tracking



lesions are better tracked by referencing accurate photos and notes over time



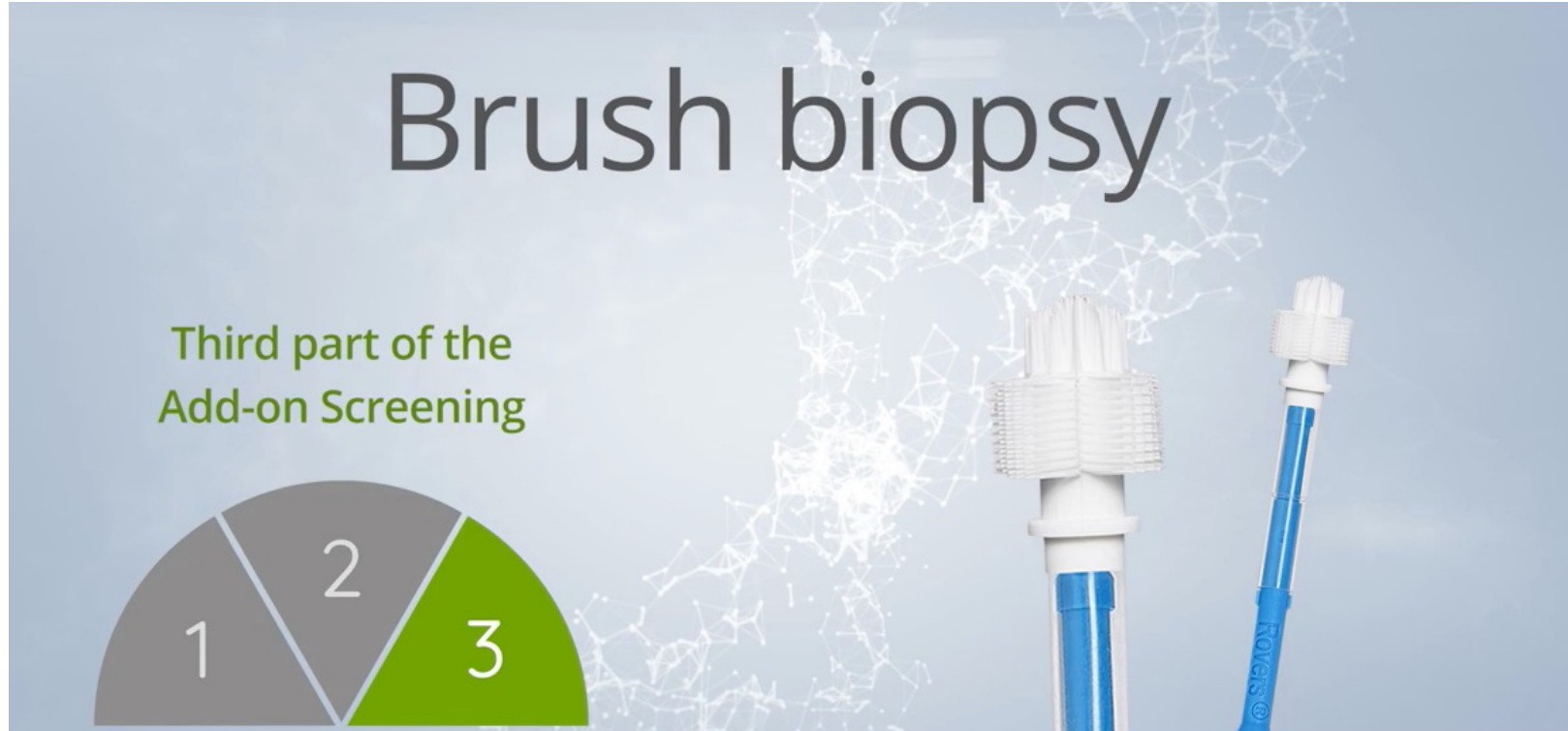
exact site can be determined by referencing the oral map

Diagnostic transparency




mouth map creates diagnostic transparency during medical care

Brush biopsy




Material for the add-on screening



Deutsche Fanconi-Anämie-Hilfe e.V.

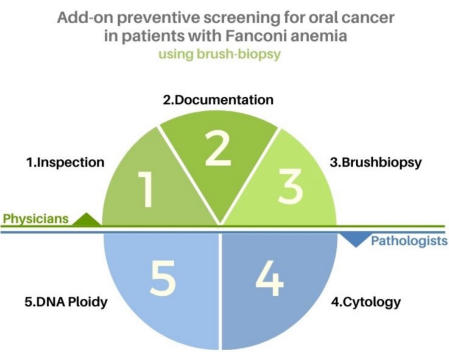
STARTFA-INFO-KITINFOPOOL ▾ORAL SCREENING...



Spenden

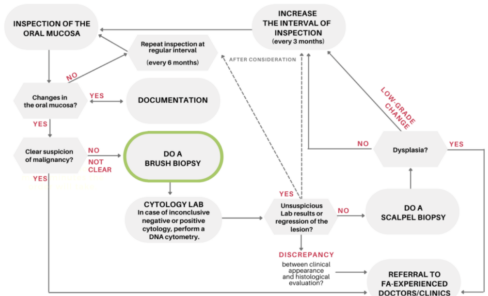
Materials & Instructions

Process of Oral Inspection	+
Process of Documentation	+
Download Oral map	+
Brush biopsy materials	+
Process of taking Brush biopsy	+
Reference Lab for FA-samples	+



➤ www.fanconi.de/scc_en

Flowchart 'Add-On Screening in Fanconi Anemia Patients and management of precursor lesions of oral squamous cell carcinoma



Basics of Add-on Screening

Study / Download	+
Step-by-Step Instructions / SOP Download	+
International FA-Guidelines	+
Regular Screeningprogram for adults with FA	+

Beddok, Velleuer et al 2025

Add-on ORAL SCREENING

TWO COMPLEMENTARY GROUPS

Infinity of screening
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PHYSICIANS

PREVENTIVE
ORAL
SCREENING

PATIENTS

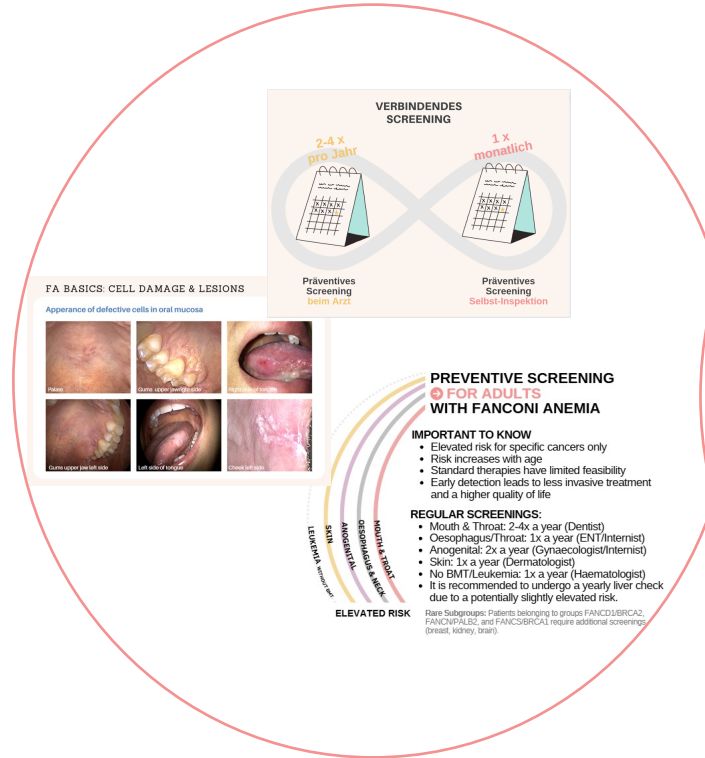
Power 2 U: Build up Self-empowerment



- Awareness & Education
- Self-Advocacy
- Lifestyle & Preventative Actions
- Emotional Resilience & Mental Strength

➤ Build up Health Literacy

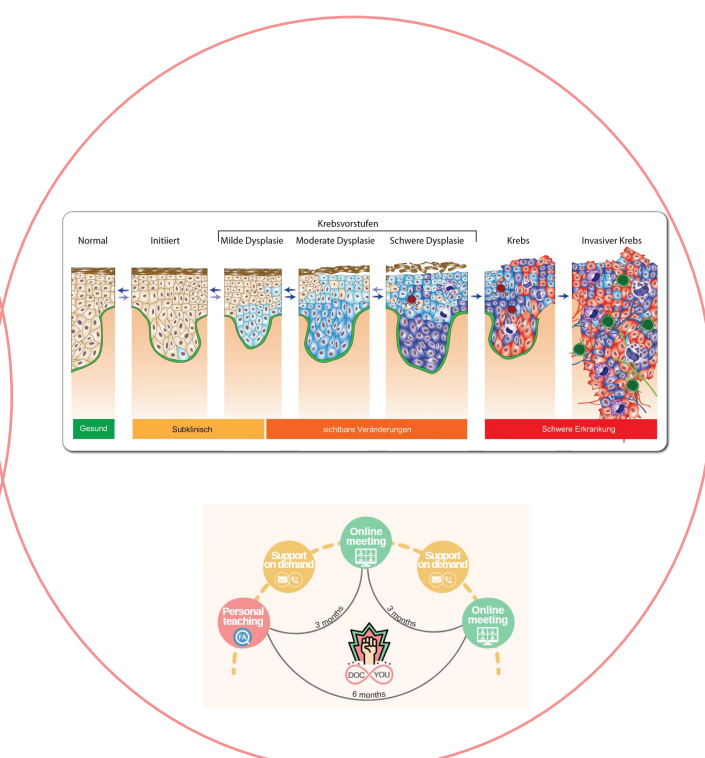
Teaching modules



Regularity

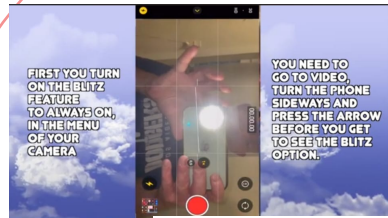


Why & how

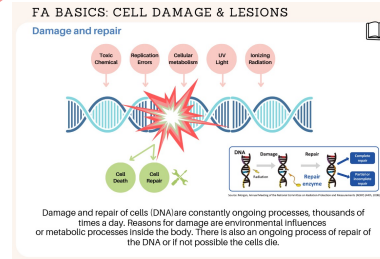


The biology

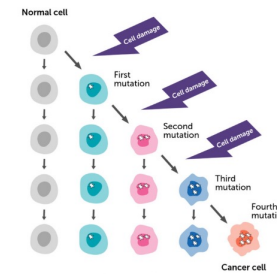
Teaching modules



FAexam

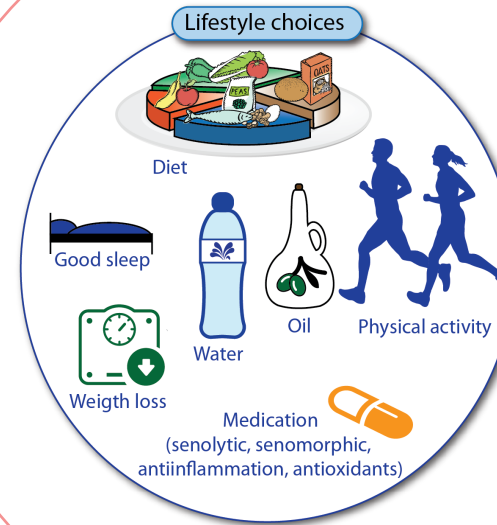


Damage and repair of cells (DNA) are constantly ongoing processes, thousands of times a day. Reasons for damage are environmental influences or metabolic processes inside the body. There is also an ongoing process of repair of the DNA or if not possible the cells die.



Adapted from "Understanding Gene Testing" - NIH 1995
When cells divide they create copies of themselves.
Over time, cells can build up enough damage to become cancer.

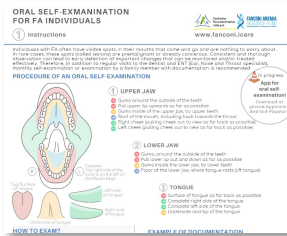
Timeline



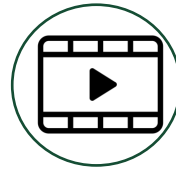
Lifestyle



Available material



Teaching material/Color Code



Video

➤ www.fanconi.de/icare



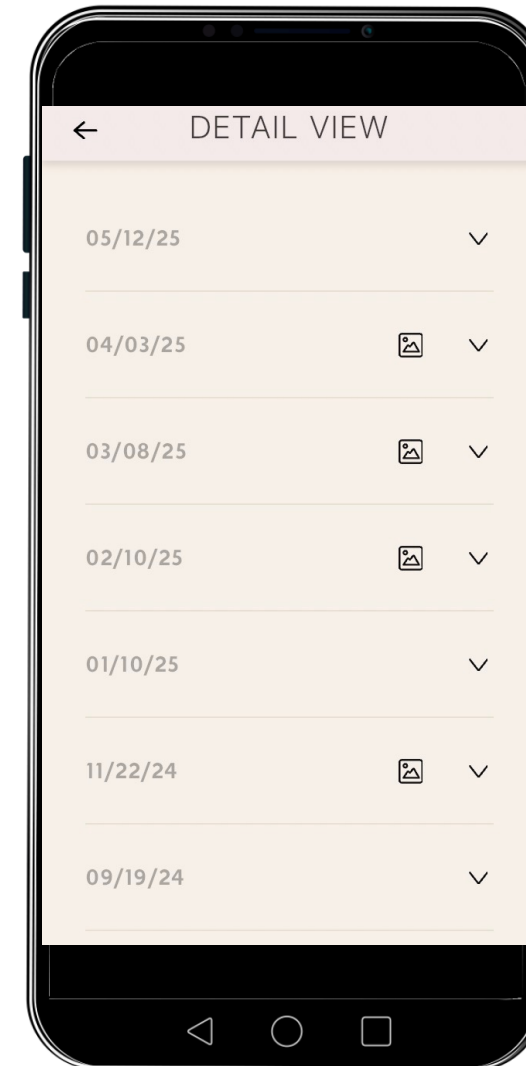
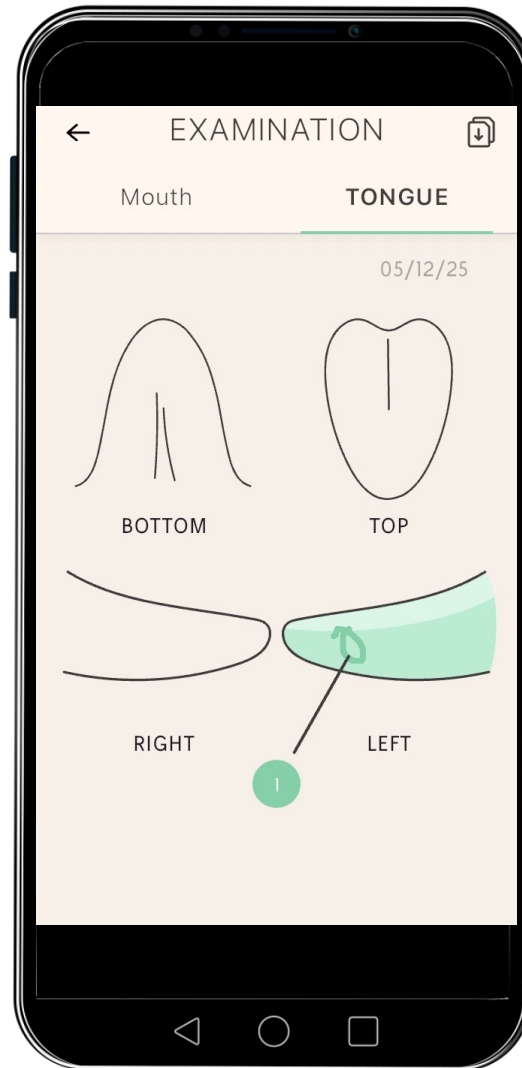
FA Wiki

➤ www.fanconi.de/faexam



App FAexam

FAexam: the application!



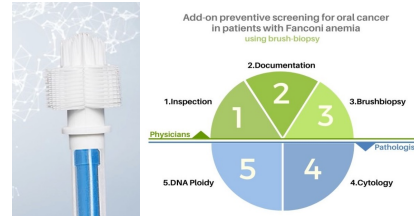
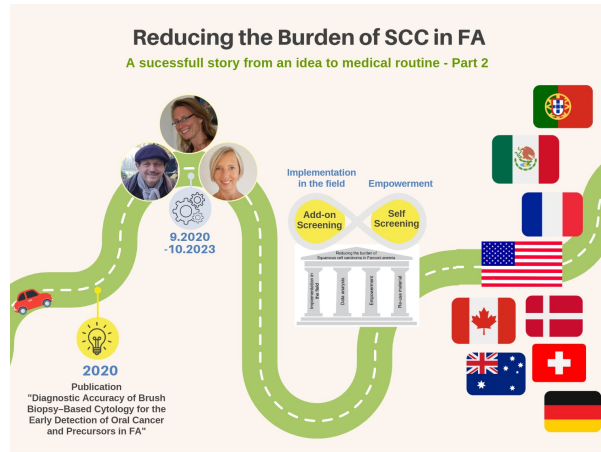


FAexam

Fanconi-Anämie / Fanconi anemia

<https://fanconi.de/faexam/>

From the past to today



Help to implement Add-on Screening in the medical field of other countries



Build up Empowerment program in patient communities of other countries



Brush biopsy:
Training purpose
& Long follow-up

THANK YOU!



WWW.FANCONI.DE/ICARE

