Appendix E Study Questionnaire

Deutsche Fanconi-Anämie-Hilfe e.V.

Reducing the burden of squamous cell carcinoma in Fanconi Anemia
- Initial study questionnaire -

Today's Date (MM/DD/YYYY): _____/_____/________

Please note: If you do not want to answer a question, leave it blank.
(*Note for minors: We are required by law to share your questionnaire with your parent(s) or guardian(s) if they ask for it.)*

1. Participant's Contact Information

Participant's First name __________________ Last name ___________________________

Gender: ☐ Male ☐ Female Date of birth (MM/DD/YYYY) _____/_____/________

(If participant is a minor: contact information of parent(s) or guardian(s)):

First name ____________________________ Last name _________________________
Street ___________________________________ City _____________________________
State _________________ Zip _____________ Country __________________________

Adult participant or parent/guardian home phone ____________________________________
Adult participant or parent/guardian mobile phone ___________________________________
Adult participant or parent/guardian email ____

2. *Treating Physician's Information*

(Alternate name and address of the physician who could receive your data report.)

Physician's name ____

Institution/Hospital ____

Street ____

City _____________________________ State _________________ Zip _______________

Telephone ________________________ Email __________________________________

3. ***Diagnosis of Fanconi Anemia***

Date of diagnosis (MM/YYYY) _____/_________

Complementation group (if known) _____________

Gene mutation(s) (if known) Maternal _______________ Paternal _______________

4. ***Summary of Medical History***

(*This information helps us understand the presentation of Fanconi anemia in your case.*)

Do you have anomalies due to FA? ☐ Yes ☐ No

(If yes, please check all that apply):

☐	Cardiac	☐	Neurological	☐	Ears/Hearing
☐	Reproductive/Gynecological	☐	Endocrine	☐	Eyes/Vision
☐	Respiratory	☐	Thumb/Radius	☐	Gastrointestinal
☐	Skeletal	☐	Growth	☐	Skin
☐	Kidney	☐	Genital	☐	Other

If other, please specify ____

In case we need more information about a specific anomaly may we contact your physician?

☐ Yes ☐ No

Do you have hematological manifestations (low blood counts)? ☐ Yes ☐ No

Age of onset of decreased blood counts: ☐ 0 – 3y ☐ 4 – 10y ☐ older than 10y

5. ***Hematological Manifestations***

(*Blood counts can help us evaluate whether you have a higher risk of infection in your mouth or a higher risk for bleeding.*)

What were your most recent blood counts?

Date (MM/DD/YYYY) ___/___/_____WBC ____ ANC _____ HGB _____ PLTS ____

Have you had a blood transfusion within the past 3 months? ☐ Yes ☐ No

Did you have unusual bleedings within the past 3 months? ☐ Yes ☐ No

If yes, please specify ____

Did you have recurrent infections within the past 3 months? ☐ Yes ☐ No

If yes, please specify ____

6. *Visible Oral Lesions*

Have you had a visible oral lesion that has stayed for at least 6 weeks?

☐ Yes ☐ No (If No, skip to question 7)

Have you consulted a doctor/dentist about the lesion(s)? ☐ Yes ☐ No

Site(s) of oral lesion(s) ____

Was a biopsy performed? ☐ Yes ☐ No

Type of diagnosed oral lesion:

☐	Leukoplakia	☐	Yeast Infection	☐	Cancer
☐	Erythroplakia	☐	Bacterial Infection	☐	Unknown
☐	Graft versus Host Disease	☐	Viral Infection	☐	Other

If other, please specify ____

If you received any treatment for your visible lesion please indicate: ___________________

____

7. *Cancer History*

Have you ever been diagnosed with squamous cell carcinoma (SCC)?

☐ Yes ☐ No (If No, skip to question 8)

Date(s) of cancer diagnosis (MM/YYYY) ____/_______ ____/_______ ____/_______

Location of cancer(s) *(please check all that apply):*

☐	Mouth	☐	Esophagus	☐	Anus	☐	Cervix
☐	Pharynx	☐	Skin	☐	Vulva	☐	Other

If other, please specify ____

Did you develop metastasis of the cancers described above? ☐ Yes ☐ No

Did you receive surgery for these cancer(s)? ☐ Yes ☐ No

If yes, Date(s) (MM/YYYY) ____/_______ ____/_______ ____/_______

Did you receive chemotherapy or equivalent? ☐ Yes ☐ No

If yes, Date(s) (MM/YYYY) ____/_______ ____/_______ ____/_______

Chemotherapy agent(s) used ______________________________________

Frequency ____

Did you receive radiation? ☐ Yes ☐ No

If yes, year(s) (YYYY) ______ ________ ________

Total Dosages (Gy) ______ ________ ________

8. ***Smoking Habits***

Have you ever smoked cigarettes regularly? ☐ Yes ☐ No (If No, skip to question 9)

Cigarettes smoked per week on average? _____

For how many years/months did you smoke regularly? Years _____ Months _____

If you stopped smoking, when did you stop (MM/YYYY)? ____/ ________

Do you (did you ever) consume regularly one ore more of the following:

☐	Pipe	☐	Water pipe	☐	Snuff	☐	Other
☐	Chewing tobacco	☐	Cigars	☐	Marijuana		

If yes to any of the above or other, please specify (kind, duration, amount, stopped, restarted):

____

9. ***Drinking Habits***

Do you (did you ever) drink alcohol occasionally or regularly?

☐ Yes ☐ No (If No, skip to question 9)

How many drinks do (did) you usually consume on a drinking day?

☐	1 drink	☐	2 drinks	☐	3 drinks	☐	4 drinks	☐	5 or more drinks

How frequently do (did) you drink alcohol?

☐	Daily	☐	2 times a week	☐	Once a month
☐	Nearly every day	☐	Once a week	☐	6-11 times a year
☐	3-4 times a week	☐	2-3 times a month	☐	1-5 times a year

What kind of drinks do/did you prefer?

☐	Beer	☐	Wine / Champagne	☐	Hard Liquor	☐	Cocktails	☐	Other

If other please specify ____

For how many years/months did you drink regularly? Years _____ Months _____

If you stopped drinking, when did you stop? (MM/YYYY) ____/ ________

Additional information about drinking habits (e.g. stopped, restarted) ________________

____

10. ***Therapy***

(*We want to find out if special kinds of treatments people with FA receive have an impact on the development of squamous cell carcinoma.)*

Did you receive any of the following treatments?

Androgens ☐ Yes ☐ No Treatment duration (MM/YYYY) ____/ _______

Growth Hormones ☐ Yes ☐ No Treatment duration (MM/YYYY) ____/ _______

Bone marrow transplant (BMT) ☐ Yes ☐ No

Date of BMT (DD/MM/YYYY) _____/_____/________

Radiation used? ☐ Yes ☐ No

Graft versus Host Disease (GvHD)? ☐ Yes Acute ☐ Yes Chronic ☐ No

Treatment agent(s) for GvHD used ___________________________________

Frequency ____

Other Therapy (please specify) _________________

Treatment duration (MM/YYYY) ____/ _____

11. ***HPV***

(*We want to find out if HPV has an impact on the development of squamous cell carcinoma in FA.*)

Have you had the HPV vaccine? ☐ Yes ☐ No If yes age(s) at vaccination ___ ___ ___

Name of vaccine: ☐ Gardasil ☐ Cervarix ☐ other (please specify) _____________

Has the participant ever had a HPV infection? ☐ Yes ☐ No ☐ Not known

12. ***Questions related to the Microbiome Study***

(Answering these questions will help us conduct the microbiome assay. Leave these questions blank if you do not want to answer.)

Did you receive one or more antibiotic treatments within the past 3 months? (Antibiotics may affect the microbiome in your mouth.)

☐ Yes ☐ No If yes, please specify:

Name of antibiotic __________________________ Treatment duration (days) ______

Name of antibiotic __________________________ Treatment duration (days) ______

Name of antibiotic __________________________ Treatment duration (days) ______

13. *Questions related to the Salivary Biomarkers Study*

(Answering these questions will help us conduct the Salivary Biomarkers study. Leave these questions blank if you do not want to answer.)

What is your ethnicity?

☐	Caucasian	☐	Asian	☐	I rather not say
☐	African American	☐	Hispanic	☐	Other

If other please specify ___________________________________

Do you have:

☐	Diabetes Type I	☐	Diabetes Type II (Insulin dependent)
☐	Hepatitis	☐	HIV

Do you have prior history of cancer (other than squamous cell carcinoma)?

☐ Yes ☐ No If yes, please describe briefly (where and date only): ______________
____

Do you have a family history of cancer? ☐ Yes ☐ No

If yes, please indicate the kind of cancer (breast, rectal, lung, etc.): ___________________
____