

## ANNUAL UPDATE FORM

**Participant Name:** \_\_\_\_\_ **IFAR number:** \_\_\_\_\_

**General Health:**

Current height: \_\_\_\_\_ (in) Current weight: \_\_\_\_\_ (lbs) Current H.C. \_\_\_\_\_ (cm)

Date of measurements: \_\_\_\_\_

Has the participant had any infections in the interim? Y/N If Y please circle all that apply:

Pneumonia	Bronchitis	CMV
Strep throat	Otitis media	EBV
Other: _____		

Has the participant had surgery in the interim? Y/N

Date: \_\_\_\_\_ Location: \_\_\_\_\_ Reason: \_\_\_\_\_  
 Date: \_\_\_\_\_ Location: \_\_\_\_\_ Reason: \_\_\_\_\_

Has the participant been hospitalized in the interim? Y/N

Date admitted: \_\_\_\_\_ Date discharged: \_\_\_\_\_ Location: \_\_\_\_\_ Reason: \_\_\_\_\_  
 Date admitted: \_\_\_\_\_ Date discharged: \_\_\_\_\_ Location: \_\_\_\_\_ Reason: \_\_\_\_\_

Is the participant followed by any new physician(s): Yes No

Name	Specialty	Hospital	Phone Number
_____	_____	_____	_____
_____	_____	_____	_____

Has the participant had the HPV vaccine since the last follow-up? Yes No

If yes, age at time of vaccine? \_\_\_\_\_

Is the participant involved in any other research studies? Yes No

Location of other research study: \_\_\_\_\_ PI: \_\_\_\_\_

**Hematologic Testing:**

Has participant had blood counts since last follow-up? Yes No I do not know

Date: \_\_\_\_\_ WBC: \_\_\_\_\_ ANC: \_\_\_\_\_ ALC: \_\_\_\_\_ HGB: \_\_\_\_\_ MCV: \_\_\_\_\_ Retic: \_\_\_\_\_ Plts: \_\_\_\_\_  
 Date: \_\_\_\_\_ WBC: \_\_\_\_\_ ANC: \_\_\_\_\_ ALC: \_\_\_\_\_ HGB: \_\_\_\_\_ MCV: \_\_\_\_\_ Retic: \_\_\_\_\_ Plts: \_\_\_\_\_

Has the participant had a bone marrow aspirate since last follow-up? Yes No

Date: \_\_\_\_\_ Cellularity: \_\_\_\_\_ % Blasts: \_\_\_\_\_ Dysplasia: \_\_\_\_\_ Cytogenetics: \_\_\_\_\_

Has the participant had a bone marrow biopsy since last follow-up? Yes No

Date: \_\_\_\_\_ Cellularity: \_\_\_\_\_ Dysplasia: \_\_\_\_\_



**Genetic/Diagnostic Testing:**

Has the participant had chromosome breakage assays in the interim? Y N

If yes: \_\_\_\_\_  
Date Laboratory Result

Has the participant had complementation testing in the interim? Y N

If yes: \_\_\_\_\_  
Date Laboratory Result

Has the participant had molecular FA testing in interim? Y N

If yes: \_\_\_\_\_  
Date Laboratory Result

Has the participant had any other genetic testing in the interim? Y N

If yes: \_\_\_\_\_  
Date Laboratory Result

**Treatment (in the interim):**

Has the participant had RBC transfusions? Y/N # of transfusions: \_\_\_\_\_

Has the participant had platelet transfusions? Y/N # of transfusions: \_\_\_\_\_

Has the participant had androgen therapy? Y/N Date started: \_\_\_\_\_ Date ended: \_\_\_\_\_

Type of androgen: \_\_\_\_\_ Dose: \_\_\_\_\_

Has the participant had treatment for diabetes? Y/N Date started: \_\_\_\_\_ Date ended: \_\_\_\_\_

Type therapy: \_\_\_\_\_ Dose: \_\_\_\_\_

Has the participant had any other hormone therapy? Y/N

Hormone: \_\_\_\_\_ Date started: \_\_\_\_\_ Date ended: \_\_\_\_\_

**Transplant:**

Has participant had a BMT since last follow-up? Y/N If yes, please answer the following:

Date of BMT: \_\_\_\_\_

Location: MSKCC MN Cincinnati Duke  
J. Hopkins CHB Hackensak Other: \_\_\_\_\_

Donor: Degree of HLA match: \_\_\_\_\_  
Related/Unrelated If related, relationship to proband: \_\_\_\_\_

Type of donation: BM PSC cord blood

BMT Prep: Chemo used? Y/N Agent: \_\_\_\_\_ Dose: \_\_\_\_\_  
Radiation used? Y/N Dose: \_\_\_\_\_  
Immunosuppressant agent? Y/N Agent: \_\_\_\_\_ Dose: \_\_\_\_\_

Complications: Fevers Infection Rash  
BK Virus EBV CMV



Nausea Mouth sores Diabetes

Other: \_\_\_\_\_

Please describe: \_\_\_\_\_

\_\_\_\_\_

Has the participant had GvHD? Y/N Acute/Chronic Grade: \_\_\_\_\_

Symptoms: \_\_\_\_\_

\_\_\_\_\_

**Cancer:**

Has the participant been diagnosed with cancer? Y/N If yes, please answer the following:

Site of cancer: Neck Mouth Pharynx Esophagus Skin

(circle all that apply): Liver Lung Kidney Prostate Anal

Colon Breast Cervix Vulva Ovary

Blood Other: \_\_\_\_\_

Other types of cancer: medulloblastoma neuroblastoma retinoblastoma

Other type of cancer: \_\_\_\_\_

Subsite: \_\_\_\_\_

Date of diagnosis: \_\_\_\_\_

Is the cancer: new recurrence metastasis Stage: \_\_\_\_\_ HPV: pos/neg/unk

Did participant have surgery? Y/N Date: \_\_\_\_\_ Tx Center: \_\_\_\_\_

Did participant have chemo? Y/N Date: \_\_\_\_\_ Tx Center: \_\_\_\_\_

Medication: \_\_\_\_\_ Dose: \_\_\_\_\_ Frequency: \_\_\_\_\_

Did participant have radiation? Y/N Date: \_\_\_\_\_ Tx Center: \_\_\_\_\_

Frequency: \_\_\_\_\_ Radiation dose: \_\_\_\_\_

**Changes in family members:**

Have any additional siblings been born in the interim? Yes No

Date of birth: \_\_\_\_\_ Gender: M/F Affected with FA: Y/N

Have any family members in the IFAR died in the interim? Yes No I do not know

Relationship to proband: \_\_\_\_\_ Name: \_\_\_\_\_

Date of death: \_\_\_\_\_ Cause of death: \_\_\_\_\_

**Other**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Completed by: \_\_\_\_\_

Date: \_\_\_\_\_

Email address: \_\_\_\_\_

Telephone: \_\_\_\_\_