



### 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

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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: \_\_\_\_\_