



Participant Name: \_\_\_\_\_

IFAR number: \_\_\_\_\_

Date report received: \_\_\_\_\_ Who was report received from? \_\_\_\_\_

Who is lab/physician listed on the report? \_\_\_\_\_ Date of visit: \_\_\_\_\_

What was obtained/received?

- Clinic note
- Hematology counts
- BM pathology
- BM cytogenetics
- Mutation report
- Complementation report
- Other genetic report
- Other pathology report
- Other lab report
- Parent update *(confirm with medical records before entering into database)*

**General Health:**

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

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

Review of Systems:

- General:
- Cardiac:
- CNS/ Neurological:
- Ears/Hearing:
- Endocrine:
- Eyes/Vision:
- Gastrointestinal:
- Genital:
- Growth:
- Kidney and urinary tract:
- Oral Cavity:
- Pain:
- Psychological:
- Reproductive/Gynecological:
- Respiratory:
- Skeletal:
- Skin:
- Spleen:
- Other:

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

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

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

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



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

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

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

Name	Specialty	Hospital	Phone Number
Name	Specialty	Hospital	Phone Number

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

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

Is the patient 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

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

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

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

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

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

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

Overall hematologic diagnosis:

Date: \_\_\_\_\_ Diagnosis: \_\_\_\_\_ Stage: \_\_\_\_\_ % Blasts: \_\_\_\_\_ Other: \_\_\_\_\_

**Genetic/Diagnostic Testing:**

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

If yes: \_\_\_\_\_

Date	Laboratory	Result

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

If yes: \_\_\_\_\_

Date	Laboratory	Result

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

If yes: \_\_\_\_\_

Date	Laboratory	Result

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

If yes: \_\_\_\_\_

Date	Laboratory	Result

**Treatment (in the interim):**

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

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

Has the patient had androgen therapy? Y/N Date started: \_\_\_\_\_ Date ended: \_\_\_\_\_  
 Type of androgen: \_\_\_\_\_ Dose: \_\_\_\_\_

Has the patient had treatment for diabetes? Y/N Date started: \_\_\_\_\_ Date ended: \_\_\_\_\_  
 Type therapy: \_\_\_\_\_ Dose: \_\_\_\_\_

Has the patient had treatment for short stature? Y/N Date started: \_\_\_\_\_ Date ended: \_\_\_\_\_  
 Type therapy: \_\_\_\_\_ Dose: \_\_\_\_\_

Has the patient had treatment for any thyroid abnormality? Y/N  
 Date started: \_\_\_\_\_ Date ended: \_\_\_\_\_  
 Type therapy: \_\_\_\_\_ Dose: \_\_\_\_\_

Has the patient 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 patient 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 patient have surgery? Y/N Date: \_\_\_\_\_ Tx Center: \_\_\_\_\_

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

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

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

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

Other notes about cancer: \_\_\_\_\_

\_\_\_\_\_

**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

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

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

**Other**

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

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

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

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

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