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

_____

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:_____