**Medications**

1. Is the participant taking any steroids by mouth currently?

No

Yes

Unknown

1. Is the participant taking any steroids by inhaler currently?

No

Yes

Unknown

1. Is the participant taking any steroids by IV currently?

No

Yes

Unknown

1. Is the participant taking any seizure medications currently?

No

Yes

Unknown

1. Is the participant taking any oral contraceptive pills (birth control pills) currently?

No

Yes

Unknown

1. Is the participant taking any estrogen forms (pill, patch, cream, other) currently?

No

Yes

Unknown

1. Is the participant taking Depo-Provera (injectable medroxyprogesterone) currently?

No

Yes

Unknown

1. Is the participant taking other progesterone forms (pill, implant, intra-uterine device, other) currently?

No

Yes

Unknown

1. Is the participant taking any testosterone (injection, patch, gel, other) or HCG (injection) currently?

No

Yes

Unknown

1. Is the participant taking any medications to stop puberty currently?

No

Yes

Unknown

1. Is the participant taking any bisphosphonates (e.g., alendronate, ibandronate, pamidronate, zoledronate, neridronate) currently?

No

Yes

Unknown

1. Has the participant ever taken a bisphosphonate (e.g., alendronate, ibandronate, pamidronate, zoledronate, neridronate) in the past?

No

Yes

Unknown

1. Is the participant taking or has ever taken teriparatide (Forteo)?

No

Yes

Unknown

1. Is the participant taking or has ever taken denosumab (Prolia)?

No

Yes

Unknown

1. Is the participant taking or has ever taken romusuzumab (Evenity)?

No

Yes

Unknown

**Dietary History**

1. What is the participant’s primary source of nutritional intake?

By mouth

By nasogastric tube

By gastric tube

By jejunal tube

Total parental nutrition (TPN)

Other, specify:

Unknown

1. Does the participant eat/drink dairy or dairy substitute products?

No

Yes

Unknown

1. Is the participant lactose intolerant?

No

Yes

Unknown

1. Is the participant taking a calcium supplement?

No

Yes

Unknown

1. Is the participant taking a vitamin D supplement?

No

Yes

Unknown

**Fracture History**

1. Has the participant ever had a fracture?

Yes

No

Unknown

* + - 1. How many fractures (if yes)?
      2. Body Site of Fracture. (Fractures of different body sites from the same instance should be recorded separately. Multiple fractures at the same body site should be recorded as 1 entry. If more than 5 fractures, enter data for the 5 most recent fractures.)

Face/skull

Rib/sternum

Upper arm/elbow

Lower arm/wrist

Hand/Fingers

Vertebra/backbone

Pelvis

Hip

Femur

Lower leg

Foot/toes

Collarbone

Other, specify:

Unknown

* + - 1. Mechanism:

Fall from standing

Fall from greater than standing

Traumatic injury (car accident, fight, etc.)

No known injury

Unknown

* + - 1. Age at Fracture (Record age in years):
      2. Fracture confirmed in medical record?

No

Yes

Recorder Signature: Date:

General Instructions

This case report form contains data elements that are collected to describe the bone health of participants.

Responses are obtained from self-report when possible or obtained from parent/legal guardian interview.

Important note: None of the data elements included on this CRF Module are classified as Core (i.e., strongly recommended for all mitochondrial disease clinical studies to collect). All data elements are classified as Supplemental and should only be collected if the research team considers them appropriate for their study.

Please see the Data Dictionary for element classifications.

Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

* For bone health evaluation, in particular for, collection and reporting of densitometry in pediatrics and adults, please see detailed guidelines at: [International Society for Clinical Densitometry](http://www.iscd.org/).
* WHO Fracture Risk Assessment Tool can be accessed at: [FRAX Tool](https://frax.shef.ac.uk/FRAX/)
* Position statements are updated regularly and can be accessed at: <https://iscd.org/learn/official-positions/>