

Section A: KEY IDENTIFYING INFORMATION

A1. Study Identification Number _____ - _____ - _____ - _____

Replaced by blinded subject ID

| | |
|----------|------------|
| blind_id | Blinded ID |
|----------|------------|

A2. Acrostic Identifier _____

Removed to protect privacy

A3. Study visit
 STUDY VISIT 11
 STUDY VISIT 22
 STUDY VISIT 3 (12 months)3
 STUDY VISIT 4 (14 months)4

| | |
|-------|-----------------|
| VISIT | A3. Study visit |
|-------|-----------------|

A4. Date of form completion _____ / _____ / _____
 M M / D D / Y Y Y Y

Replaced by age at date of form completion, days

| | |
|----------|---|
| R106_age | <created var>Age at date of form completion, days |
|----------|---|

A5. Name of person completing form _____
 PRINT FULL NAME INITIALS

Removed to protect privacy

Section B: FINDINGS

B1. Date of evaluation _____ / _____ / _____
 M M / D D / Y Y Y Y

| | |
|-----------|--|
| geval_age | B1 <created var> Age at date of evaluation, days |
|-----------|--|

B2. Length _____ . _____ cm

| | |
|---------------|---|
| HT_GEVAL | B2. Length |
| GEVAL_haz_who | <created var> Length/height-for-age z-score (WHO) |

B3. Weight _____ . _____ kg

| | |
|---------------|--|
| WT_GEVAL | B3. Weight |
| GEVAL_waz_who | <created var> Weight-for-age z-score (WHO) |

B4. Head Circumference _____ . _____ cm

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(Not All Dataset Variables are Shown)

| | |
|---------------|--|
| HC_GEVAL | B4. Head circumference |
| GEVAL_haz_who | <created var> Head circumference-for-age z score (WHO) |

B5. Normal Exam YES..... 1 NO2

| | |
|------------|-----------------|
| NORM_GEVAL | B5. Normal exam |
|------------|-----------------|

Section C: ABNORMALITIES

C1. Has patient's karyotype already been assessed for the trial? YES..... 1 (C3) NO2

| | |
|---------|---|
| KARYOYN | C1. Has patient's karyotype already been assessed |
|---------|---|

C2. Karyotype 46 XY1
46 XX2
OTHER99

a. Specify: _____

| | |
|----------|-------------------------|
| KARYOTYP | C2. Karyotype |
| KARYO_S | C2a. Karyotype: Specify |

C3. Does patient have an identifiable syndrome? YES..... 1 NO2 (C4)

| Identified Syndromes | | | |
|----------------------|-----------------------------|------|----------------------------|
| Code | Name | Code | Name |
| 01 | Alagille Syndrome | 09 | Noonan's Syndrome |
| 02 | CHARGE association | 10 | Smith-Lemle-Opitz |
| 03 | DiGeorge Syndrome | 11 | Treacher Collins Syndrome |
| 04 | Down Syndrome | 12 | Turner Syndrome |
| 05 | Ellis –Van Crevald Syndrome | 13 | VATER/VACTERAL Association |
| 06 | Goldenhar Syndrome | 14 | Williams Syndrome |
| 07 | Holt-Oram Syndrome | | |
| 08 | Jacobsen's Syndrome | 99 | Other, identifiable |

Code identifiable syndrome (See codes above)

a. ____ 1. If Other (99), specify: _____

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| | |
|----------|---|
| SYNDROM | C3. Does patient have an identifiable syndrome |
| SYNDCODE | C3a. Does patient have an identifiable syndrome: Code |
| SYNDRM_S | C3a1. Code: Specify |

C4. Were any abnormalities detected that are not part of an identifiable syndrome? YES..... 1 NO2 (END)

Code Abnormality (Use Code list L)

- a. ___ - ___ ___ ___ ___ 1. If Other, specify: _____
- b. ___ - ___ ___ ___ ___ 1. If Other, specify: _____
- c. ___ - ___ ___ ___ ___ 1. If Other, specify: _____
- d. ___ - ___ ___ ___ ___ 1. If Other, specify: _____
- e. ___ - ___ ___ ___ ___ 1. If Other, specify: _____
- f. ___ - ___ ___ ___ ___ 1. If Other, specify: _____
- g. ___ - ___ ___ ___ ___ 1. If Other, specify: _____
- h. ___ - ___ ___ ___ ___ 1. If Other, specify: _____

| | |
|------------|--|
| ABNORM | C4. Were there any abnormalities detected |
| abnorcod | <created var> Concatenation of all abnormality codes |
| ABNORCOD_0 | C4.a Code Abnormality |
| ABNORM_S_0 | C4.a Code Abnormality, if other specify |
| ABNORCOD_1 | C4.b Code Abnormality |
| ABNORM_S_1 | C4.b Code Abnormality, if other specify |

...

| | |
|------------|---|
| ABNORCOD_7 | C4.h Code Abnormality |
| ABNORM_S_7 | C4.h Code Abnormality, if other specify |
| ABNORCOD_8 | C4.i Code Abnormality |
| ABNORM_S_8 | C4.i Code Abnormality, if other specify |

<created variables>

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| | |
|--------------|---|
| syndrom_ever | <created var> Ever had an identifiable syndrome |
| abnorm_ever | <created var> Ever had any abnormalities |