

**INSTRUCTIONS: After baseline, this form must be completed for all subjects at each study visit.**

**Section A: KEY IDENTIFYING INFORMATION**

A1. Study Identification Number \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

A2. Study visit  
 STUDY VISIT 1 (Month 6) .....1  
 STUDY VISIT 2 (Month 12) .....2  
 STUDY VISIT 3 (Month 24) .....3  
 STUDY VISIT 4 (Month 36) .....4

A3. Date of form completion  
 \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
 M M D D Y Y Y Y

A4. Name of person completing form  
 \_\_\_\_\_  
 PRINT FULL NAME INITIALS

A5. Date of visit  
 \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
 M M D D Y Y Y Y

**Section B: CLINICAL ASSESSMENT AT TIME OF STUDY VISIT**

**If Measures 1 & 2 for questions B1 and B2 differ by more than the stated amount in the "Difference" column, a 3rd measurement must be taken.**

	a. Measure 1	b. Measure 2	Difference	c. Measure 3
B1. Weight (kg)	_____ . _____	_____ . _____	> 0.1 kg →	_____ . _____
B2. Height/ Length (cm)	_____ . _____	_____ . _____	> 1.0 cm →	_____ . _____
d. How was height measured?		STANDING.....1 RECUMBENT.....2		
B3. Arm span		_____ . _____ cm		
B4. Lower segment		_____ . _____ cm		

**Section C: INTERIM MEDICAL HISTORY**

***In Section C, please indicate if there are manifestations of Marfan syndrome in the subject or any changes to the subject's condition since the last study visit.***

C1.	Are there new or worsening skeletal manifestations?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Pectus carinatum (worsening from previous assessment)	1	2	-8
b.	Pectus excavatum (worsening from previous assessment)	1	2	-8
c.	Scoliosis > 20° OR spondylolisthesis (worsening from previous assessment)	1	2	-8
d.	Protrusio acetabuli of any degree (ascertained on radiographs) (worsening from previous assessment or newly diagnosed)	1	2	-8
e.	Other	1	2 (C2)	-8 (C2)

i. Specify \_\_\_\_\_

C2.	Any new ocular findings?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Ectopia lentis	1	2	-8
b.	Flat cornea	1	2	-8
c.	Increased axial length of the globe	1	2	-8
d.	Hypoplastic iris OR hypoplastic ciliary muscle causing decreased miosis	1	2	-8
e.	Other	1	2 (C3)	-8 (C3)

i. Specify \_\_\_\_\_

C3.	Any new pulmonary findings?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Spontaneous pneumothorax	1	2	-8
b.	Apical blebs (by chest X-ray, CT or MRI)	1	2	-8
c.	Other	1	2 (C4)	-8 (C4)

i. Specify \_\_\_\_\_

C4.	Any new skin and integument findings?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Striae distensae	1	2	-8
b.	Recurrent or incisional hernia	1	2	-8
c.	Other	1	2 (C5)	-8 (C5)

i. Specify \_\_\_\_\_

C5.	Newly diagnosed dural ectasia?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Lumbrosacral dural ectasia (by CT or MRI)	1	2	-8

  

C6.	New FBN1 mutation data?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Presence of a mutation in FBN1 known to cause Marfan syndrome?	1	2	-8

  

C7.	Any new neurodevelopmental problems?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Attention deficit requiring medication	1	2	-8
b.	Hyperactivity requiring medication	1	2	-8
c.	Developmental delay requiring special therapy	1	2	-8
d.	Learning differences, requiring special education or special services	1	2	-8
e.	Other	1	2 (C8)	-8 (C8)
i.	Specify			

  

C8.	Any new psychiatric issues?	<b>YES</b>	<b>NO</b>	<b>UNKNOWN</b>
a.	Depression requiring therapy	1	2	-8
b.	Other requiring therapy	1	2 (D1)	-8 (D1)
i.	Specify			

**Section D: SURGICAL HISTORY**

- D1. Has the subject had any cardiac surgeries since the last study visit? YES ..... 1 NO ..... 2 **(E1)**
- a. AV valve surgery? YES ..... 1 NO ..... 2
- b. Other cardiac surgery? YES ..... 1 NO ..... 2 **(E1)**
- i. Specify \_\_\_\_\_

**Section E: CURRENT MEDICATIONS****List current daily medications**

- E1. How many daily medications has the subject STOPPED taking since the last study visit? \_\_\_\_\_ (0-4) **(If 0, then go to E2)**  
 (Research Coordinator to review all medications recorded at the time of the last visit)

A. Medication Code Codelist D	B. Medication Name Worksheet (Specify name if Medication Code ends in "99")	C. Date Medication STOPPED (M M / Y Y Y Y)
1. ____ . ____		____ / ____
2. ____ . ____		____ / ____
3. ____ . ____		____ / ____
4. ____ . ____		____ / ____

E2. How many NEW medications has the subject STARTED taking since the last study visit?

(Research Coordinator to review all medications recorded at the time of the last visit)

\_\_ \_\_ (0-4) (If 0,  
then go to E3)

A. Medication Code Codelist D	B. Medication Name Worksheet (Specify name if Medication Code ends in "99")	C. Date Medication STARTED (M M / Y Y Y Y)	D. Dose (mg/day) Record -8 if dose unknown
1. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _
2. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _
3. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _
4. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _

E3. How many dosage changes to the subject's current medications have there been since the last study visit?

(Research Coordinator to review all medications recorded at the time of the last visit)

\_\_ \_\_ (0-4) (If 0,  
then go to Z1)

A. Medication Code Codelist D	B. Medication Name Worksheet (Specify name if Medication Code ends in "99")	C. Date of DOSE CHANGE (M M / Y Y Y Y)	D. Current Dose (mg/day) Record -8 if dose unknown
1. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _
2. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _
3. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _
4. _ _ . _ _		_ _ / _ _ _ _	_ _ . _ _

### Section Z: TIME TO COMPLETE FORM

Z1. How long did it take to complete this form?

\_ \_ : \_ \_  
H H M M