

INSTRUCTIONS: This form must be completed for all consenting subjects at the time of entry into the Marfan Trial.

Section A: KEY IDENTIFYING INFORMATION

- A1. Study Identification Number _____ - _____ - _____ - _____ - _____
- A2. Study visit BASELINE(0)
- a. What number screening is this? _____
- 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
- A6. Does this subject have any biological relatives with known or suspected Marfan syndrome?
 YES..... 1
 NO 2 (Z1)
 UNKNOWN -8 (Z1)

If question A6 = NO or UNKNOWN (subject has no biological relatives with known or suspected Marfan syndrome), then SKIP TO Z1.

If question A6 = YES, then complete the family history questions below for any and all first-degree biological relatives and/or grandparents with known or suspected Marfan syndrome. Indicate the relationship using the codes below. Provide answers for all of the questions (a-g) even if the response is 'UNKNOWN'.

To report age: Round to the nearest full year; Round up to the nearest year if ≥ 6 months; Round down for < 6 months (e.g., if relative is 33 years and 8 months old at the time of aortic surgery, report relative's age as 34 years).

If family includes more than 3 relatives with Marfan syndrome, then make additional copies of page 4 of this form and complete the information.

Code	Relationship to Subject	Code	Relationship to Subject
1	Mother	7	Maternal Grandmother
2	Father	8	Paternal Grandmother
3	Sister	9	Maternal Grandfather
4	Brother	10	Paternal Grandfather
5	Son		
6	Daughter		

Section B: FAMILY HISTORY

B1. How many biological relatives with known or suspected Marfan syndrome? _____

a. Relative #1 code _____

b. Aortic Aneurysm YES 1
 NO 2 (c)
 UNKNOWN.....-8 (c)

1. Location of aneurysm AORTIC ROOT/ASCENDING AORTA.. 1
 DESCENDING AORTA/ABDOMINAL... 2
 BOTH..... 3
 UNKNOWN.....-8

c. Aortic dissection YES 1
 NO 2 (d)
 UNKNOWN.....-8 (d)

1. Location of dissection AORTIC ROOT/ASCENDING AORTA.. 1
 DESCENDING AORTA/ABDOMINAL... 2
 BOTH..... 3
 UNKNOWN.....-8

d. Aortic surgery YES 1
 NO 2 (e)
 UNKNOWN.....-8 (e)

1. Location of surgery AORTIC ROOT/ASCENDING AORTA.. 1
 DESCENDING AORTA/ABDOMINAL... 2
 BOTH..... 3
 UNKNOWN.....-8

2. Age at first surgery _____ Years
 (-8 if unknown)

e. Mitral valve surgery YES 1
 NO 2
 UNKNOWN.....-8

f. Ectopia lentis YES 1
 NO 2
 UNKNOWN.....-8

g. Is this relative alive today? YES 1 (a)
 NO 2
 UNKNOWN.....-8 (a)

1. Cause of death AORTIC DISSECTION..... 1
 OTHER CARDIAC 2
 NON-CARDIAC 3
 SUDDEN, CAUSE UNKNOWN..... 4

2. Age at death _____ Years
 (-8 if unknown)

a.	Relative #2 code	_____	_____		
b.	Aortic Aneurysm	YES	1		
		NO	2 (c)		
		UNKNOWN.....	-8 (c)		
		1. Location of aneurysm		AORTIC ROOT/ASCENDING AORTA..	1
				DESCENDING AORTA/ABDOMINAL ...	2
		BOTH.....	3		
		UNKNOWN.....	-8		
<hr/>					
c.	Aortic dissection	YES	1		
		NO	2 (d)		
		UNKNOWN.....	-8 (d)		
		1. Location of dissection		AORTIC ROOT/ASCENDING AORTA..	1
				DESCENDING AORTA/ABDOMINAL ...	2
		BOTH.....	3		
		UNKNOWN.....	-8		
<hr/>					
d.	Aortic surgery	YES	1		
		NO	2 (e)		
		UNKNOWN.....	-8 (e)		
		1. Location of surgery		AORTIC ROOT/ASCENDING AORTA..	1
				DESCENDING AORTA/ABDOMINAL ...	2
		BOTH.....	3		
		UNKNOWN.....	-8		
		2. Age at first surgery	_____ Years		
			(-8 if unknown)		
<hr/>					
e.	Mitral valve surgery	YES	1		
		NO	2		
		UNKNOWN.....	-8		
<hr/>					
f.	Ectopia lentis	YES	1		
		NO	2		
		UNKNOWN.....	-8		
<hr/>					
g.	Is this relative alive today?	YES	1 (a)		
		NO	2		
		UNKNOWN.....	-8 (a)		
		1. Cause of death		AORTIC DISSECTION.....	1
				OTHER CARDIAC	2
		NON-CARDIAC	3		
		SUDDEN, CAUSE UNKNOWN.....	4		
		2. Age at death	_____ Years		
			(-8 if unknown)		

- a. Relative #3 code _____

- b. Aortic Aneurysm
 - YES 1
 - NO 2 (c)
 - UNKNOWN.....-8 (c)
 - 1. Location of aneurysm
 - AORTIC ROOT/ASCENDING AORTA.. 1
 - DESCENDING AORTA/ABDOMINAL... 2
 - BOTH..... 3
 - UNKNOWN.....-8

- c. Aortic dissection
 - YES 1
 - NO 2 (d)
 - UNKNOWN.....-8 (d)
 - 1. Location of dissection
 - AORTIC ROOT/ASCENDING AORTA.. 1
 - DESCENDING AORTA/ABDOMINAL... 2
 - BOTH..... 3
 - UNKNOWN.....-8

- d. Aortic surgery
 - YES 1
 - NO 2 (e)
 - UNKNOWN.....-8 (e)
 - 1. Location of surgery
 - AORTIC ROOT/ASCENDING AORTA.. 1
 - DESCENDING AORTA/ABDOMINAL... 2
 - BOTH..... 3
 - UNKNOWN.....-8
 - 2. Age at first surgery
 - _____ Years
 - (-8 if unknown)

- e. Mitral valve surgery
 - YES 1
 - NO 2
 - UNKNOWN.....-8

- f. Ectopia lentis
 - YES 1
 - NO 2
 - UNKNOWN.....-8

- g. Is this relative alive today?
 - YES 1 (Z1)
 - NO 2
 - UNKNOWN.....-8 (Z1)
 - 1. Cause of death
 - AORTIC DISSECTION..... 1
 - OTHER CARDIAC 2
 - NON-CARDIAC 3
 - SUDDEN, CAUSE UNKNOWN..... 4
 - 2. Age at death
 - _____ Years
 - (-8 if unknown)

Section Z: TIME TO COMPLETE FORM AND SIGNATURE

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

Signature of PI: _____ Date: _____

END OF FORM