Marfan Data Codebook
A216: Permanent Withdrawal From Trial
(raw data)

DATE CREATED 13SEP18
Number of Observations: 66
Number of Variables: 17
Organization of file: One Record per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
A1. Random identification number	RANDOM_ID			66(0)			144508.00-145870.00
A2. Last visit at which subject completed any study measures	VISIT	BASELINE	13(19.7)				
		STUDY VISIT 1 (Month 6)	8(12.1)				
		STUDY VISIT 2 (Month 12)	17(25.8)				
		STUDY VISIT 3 (Month 24)	28(42.4)				
A2a. Age of subject at last seen for trial	LASTSEEN_AGE			66(0)	16.09(6.52)	15.65(12.80,19.60)	1.90-27.80
B1. Age at study withdrawal	WD_AGE			66(0)	16.70(6.62)	16.55(13.00,20.10)	2.30-29.40
B2. Age at last dose of study drug taken	LSTDRUG_AGE			55(11)	16.74(5.81)	16.70(13.20,19.70)	0.80-28.70
B3. Last dose of study drug taken	LSTDOSE			59(7)	89.75(59.85)	75.00(50.00,100.00)	3.00-250.00
B4. Primary indication for withdrawal from trial	WD_RSN	OTHER	3(4.5)				
		PHYSICIAN WITHDREW SUBJECT FOR OTHER REASON	6(9.1)				
		SUBJECT DEATH	1(1.5)				

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		SUBJECT HAD AN AORTIC DISSECTION	2(3.0)				
		SUBJECT LOST TO FOLLOW-UP	11(16.7)				
		SUBJECT OR FAMILY WITHDREW FROM TRIAL	17(25.8)				
		SUBJECT REQUIRED AORTIC ROOT SURGERY	26(39.4)				
B4b. Primary reason family (subject) is withdrawing from trial	WD_FMRSN	INTOLERANCE TO STUDY DRUG	1(1.5)				
		OTHER	9(13.6)				
		SKIPPED	49(74.2)				
		TAKING TOO MUCH TIME	1(1.5)				
		TRAVEL DISTANCE TO/FROM CENTER	6(9.1)				
B4c. Age at aortic dissection	AORTICDIS_AGE			2(64)	19.60(9.05)	19.60(13.20,26.00)	13.20-26.00
B4ci. Did subject survive aortic dissection?	SURVIVE_DIS	SKIPPED	64(97.0)				
		YES	2(3.0)				
B4d. Age at aortic root surgery	ROOTSURG_AGE			28(38)	17.33(4.32)	16.60(13.55,19.55)	12.90-26.00

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B4di. Did subject survive the aortic root surgery?	SURVIVE_SURG	SKIPPED	38(57.6)				
		YES	28(42.4)				
B4e. Primary cause of death	DEATH	CARDIAC	1(1.5)				
		SKIPPED	65(98.5)				
B4e1. Cause of death (CTCAE Code)	DEATHCODE	9E7	1(1.5)				
		SKIPPED	65(98.5)				
B4e2. Specify cause of death (CTCAE short name)	DEATHNAME	Heart failure	1(1.5)				
		SKIPPED	65(98.5)				
B4e3. Source of vital status	VITAL	MD/HOSPITAL RECORDS	1(1.5)				
		SKIPPED	65(98.5)				
Form Version	VER_ID	A	66(100.0)				