

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records 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			730(0)			144502.00-145870.00
A2. Study visit	VISIT	BASELINE	730(100.0)				
A2a. What number screening is this?	SCREEN_NUM	1	667(91.4)				
		2	59(8.1)				
		3	4(0.5)				
A5. Age at visit	VISIT_AGE			730(0)	11.26(6.36)	10.90(6.10,15.80)	0.50-26.00
B1a. Skeletal System: Pectus carinatum	PECTUS_C103	NO	424(58.1)				
		UNKNOWN	1(0.1)				
		YES	305(41.8)				
B1b. Skeletal System: Pectus excavatum	PECTUS_E103	NO	540(74.0)				
		UNKNOWN	3(0.4)				
		YES	187(25.6)				
B1c. Skeletal Syst.: Reduced seg. ratio OR arm span/ht ratio>1.05	RATIO	NO	234(32.1)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		UNKNOWN	45(6.2)				
		YES	451(61.8)				
B1d. Skeletal System: Wrist AND thumbs signs	WRIST_THMB	NO	207(28.4)				
		UNKNOWN	25(3.4)				
		YES	498(68.2)				
B1e. Skeletal System: Scoliosis > 20° OR spondylolisthesis	SCOLIOSIS103	NO	466(63.8)				
		UNKNOWN	43(5.9)				
		YES	221(30.3)				
B1f. Skeletal System: Reduced extension at the elbow (<170°)	EXT_ELBOW	NO	496(67.9)				
		UNKNOWN	29(4.0)				
		YES	205(28.1)				
B1g. Skeletal System: Medial rotation of the medial malleolus	MEDROTAT	NO	203(27.8)				
		UNKNOWN	25(3.4)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		YES	502(68.8)				
B1h. Skeletal System: protrusio acetabuli of any degree	PROTRUSIO103	NO	104(14.2)				
		UNKNOWN	595(81.5)				
		YES	31(4.2)				
B1i. Skeletal System: Mild pectus excavatum	MILDPEXCAV	NO	598(81.9)				
		UNKNOWN	13(1.8)				
		YES	119(16.3)				
B1j. Skeletal System: Joint hypermobility	JOINTHYPMOB	NO	121(16.6)				
		UNKNOWN	23(3.2)				
		YES	586(80.3)				
B1k. Skeletal System: Highly arched palate	ARCHPALATE	NO	105(14.4)				
		UNKNOWN	16(2.2)				
		YES	609(83.4)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B1l. Skeletal System: Facial	FACIAL	NO	137(18.8)				
		UNKNOWN	15(2.1)				
		YES	578(79.2)				
B2a. Ocular System: Ectopia lentis	E_LENTIS103	NO	347(47.5)				
		UNKNOWN	101(13.8)				
		YES	282(38.6)				
B2b. Ocular System: Flat cornea	CORNEA103	NO	223(30.5)				
		UNKNOWN	498(68.2)				
		YES	9(1.2)				
B2c. Ocular System: Increased axial length of the globe	GLOBE103	NO	201(27.5)				
		UNKNOWN	507(69.5)				
		YES	22(3.0)				
B2d. Ocular System: Hypoplastic iris/ciliary muscle	HYPPO_IRIS103	NO	226(31.0)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		UNKNOWN	497(68.1)				
		YES	7(1.0)				
B3a. CV System: Mitral valve prolapse	MVPROLAPSE	NO	288(39.5)				
		UNKNOWN	10(1.4)				
		YES	432(59.2)				
B3b. CV System: Main pulmonary artery Z-score > 2.0	PULM_ART	NO	308(42.2)				
		UNKNOWN	325(44.5)				
		YES	97(13.3)				
B3c. CV System: Calcification of the mitral annulus	MITRAL_ANNUL	NO	593(81.2)				
		UNKNOWN	135(18.5)				
		YES	2(0.3)				
B3d. CV System: Dilatation of the descending aorta	DESC_AORTA	NO	499(68.4)				
		UNKNOWN	185(25.3)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		YES	46(6.3)				
B4a. Pulmonary System: Spontaneous pneumothorax	THORAX103	NO	678(92.9)				
		UNKNOWN	26(3.6)				
		YES	26(3.6)				
B4b. Pulmonary System: Apical blebs	BLEBS103	NO	308(42.2)				
		UNKNOWN	413(56.6)				
		YES	9(1.2)				
B5a. Skin and Integument: Striae distensae	STRIAE103	NO	428(58.6)				
		UNKNOWN	11(1.5)				
		YES	291(39.9)				
B5b. Skin and Integument: Recurrent or incisional hernia	HERNIA103	NO	678(92.9)				
		UNKNOWN	16(2.2)				
		YES	36(4.9)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B6a. Dura: Lumbosacral dural ectasia	DURAL103	NO	84(11.5)				
		UNKNOWN	611(83.7)				
		YES	35(4.8)				
B7a. Family and genetic history: First degree relative	RELATIVE	NO	305(41.8)				
		UNKNOWN	83(11.4)				
		YES	342(46.8)				
B7b. Family and genetic history: Presence of mutation in FBN1	MUTATION103	NO	56(7.7)				
		UNKNOWN	468(64.1)				
		YES	206(28.2)				
B7c. Family/genetic history: Presence of a haplotype around FBN1	HAPLOTYPE	NO	113(15.5)				
		UNKNOWN	575(78.8)				
		YES	42(5.8)				
B8a. Craniosynostosis (SGS and LDS)	CRANIOSYN	NO	725(99.3)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		YES	5(0.7)				
B8b. Hypertelorism (SGS and LDS)	HYPTELORISM	NO	711(97.4)				
		YES	19(2.6)				
B8c. Mental retardation (SGS and LDS)	MENTALRET	NO	726(99.5)				
		YES	4(0.5)				
B8d. Cleft palate (LDS)	CLEFTPALATE	NO	728(99.7)				
		YES	2(0.3)				
B8e. Bifid uvula (split or central raphe) (LDS)	BIFIDUVULA	<i>Missing</i>	1(0.1)				
		NO	721(98.8)				
		YES	8(1.1)				
B8f. Club foot (SGS and LDS)	CLUBFOOT	NO	722(98.9)				
		YES	8(1.1)				
B8g. Documented arterial tortuosity (LDS)	TORTUOSITY	NO	571(78.2)				



**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		UNKNOWN	151(20.7)				
		YES	8(1.1)				
B8h. Chiari malformation (SGS and LDS)	CHIARI	NO	501(68.6)				
		UNKNOWN	227(31.1)				
		YES	2(0.3)				
B8i. Cervial spine instability (LDS)	CERVICSPINE	NO	517(70.8)				
		UNKNOWN	211(28.9)				
		YES	2(0.3)				
B9. Would you like to file an appeal?	APPEAL	N/A	693(94.9)				
		NO	12(1.6)				
		YES	25(3.4)				
B10. Is the subject eligible to proceed with screening?	ELIGIBLE103	NO	12(1.6)				
		SKIPPED	25(3.4)				
		YES	693(94.9)				

**Marfan Data Codebook**  
**A103: Ghent Criteria**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 730**

**Number of Variables: 44**

**Organization of file: Up to Three Records per Patient**

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
Form Version	VER_ID	A	48(6.6)				
		B	682(93.4)				