Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven 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			168(0)			144519.00-145870.00
A2. Study drug assigned	STUDYDRUG210	STUDY DRUG A	85(50.6)				
		STUDY DRUG B	78(46.4)				
		Version	5(3.0)				
A3a. Type of cycle for study drug A	ACYCLE210	CYCLE 1a	1(0.6)				
		CYCLE 1b	4(2.4)				
		CYCLE 2	6(3.6)				
		CYCLE 3	2(1.2)				
		CYCLE 4	4(2.4)				
		MAINTENANCE	68(40.5)				
		SKIPPED	78(46.4)				
		Version	5(3.0)				
A3b. Type of cycle for study drug B	BCYCLE210	CYCLE 1	4(2.4)				
		CYCLE 2	4(2.4)				
		CYCLE 3	1(0.6)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		MAINTENANCE	69(41.1)				
		SKIPPED	85(50.6)				
		Version	5(3.0)				
A4. Prescription number (must match Rx # on A120 form)	RX_NUM210	1	4(2.4)				
		2	7(4.2)				
		3	5(3.0)				
		4	12(7.1)				
		5	16(9.5)				
		6	15(8.9)				
		7	14(8.3)				
		8	10(6.0)				
		9	15(8.9)				
		10	13(7.7)				
		11	7(4.2)				
		12	9(5.4)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		13	7(4.2)				
		14	12(7.1)				
		15	6(3.6)				
		16	1(0.6)				
		17	4(2.4)				
		18	1(0.6)				
		20	1(0.6)				
		22	2(1.2)				
		24	1(0.6)				
		40	1(0.6)				
		Version	5(3.0)				
B1. Stop number	DRSTOPNUM	1	93(55.4)				
		2	28(16.7)				
		3	20(11.9)				
		4	15(8.9)				
		5	7(4.2)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		6	4(2.4)				
		7	1(0.6)				
B2. Age when last dose of study taken	DRSTOP_AGE			167(1)	12.78(6.86)	12.60(6.60,18.80)	1.10-27.70
B3. Primary reason study drug stopped temporarily	DRSTOPRSN	ACUTE ILLNESS	5(3.0)				
		DIZZINESS	3(1.8)				
		NPO STATUS	3(1.8)				
		OTHER	155(92.3)				
		S.O.B./DYSPNEA	1(0.6)				
		WHEEZING/BRONCHOSPASM	1(0.6)				
B3a. Specify other: reason drug temporarily stopped	DRSTOPRSN_SP	"Pill too big" according to patient	1(0.6)				
		acute epistaxis requiring blood transfusion	1(0.6)				
		as ordered per ophth. md prior to pending surgery	1(0.6)				
		bilateral pedal edema	1(0.6)				
		complicated reasoning too long for 50 characters	1(0.6)				
		daily nausea and vomiting. (see AE)	1(0.6)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		decreased platelet count and decrease WBC.	1(0.6)				
		depression	1(0.6)				
		Depression	1(0.6)				
		Depression; Anxiety	1(0.6)				
		did not call for a refill	1(0.6)				
		Did not have study drug available.	1(0.6)				
		did not respond or call for refill	7(4.2)				
		extensive eczema	1(0.6)				
		Falling, "spacing out"	1(0.6)				
		FAMILY TRAVELING FOR HOLIDAYS	1(0.6)				
		FATIGUE AND AGITATION	1(0.6)				
		fatigue daily headaches mood changes sleep walking	1(0.6)				
		Fatigue for ~10 days with 1 episode of syncope.	1(0.6)				
		fed ex package not delivered	1(0.6)				
		Field Comment	1(0.6)				
		Flu vomiting and fever	1(0.6)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		forgot refill	1(0.6)				
		Gap between prescriptions	1(0.6)				
		Gap in prescription	5(3.0)				
		Gap in prescriptions	1(0.6)				
		Hives. Medication stopped by PCP.	1(0.6)				
		hospitalization & hypotension while inpatient	1(0.6)				
		in hospital pelvis fracture.	1(0.6)				
		Insomnia	1(0.6)				
		intermittent NC	2(1.2)				
		isomnia	1(0.6)				
		MEDICATION SPILLED IN DIAPER BAG	1(0.6)				
		NC pt missed doses intermittenly	1(0.6)				
		NC pt missed doses intermittently not continuously	1(0.6)				
		Nightmares	1(0.6)				
		no study drug on hand	1(0.6)				
		non compliance	10(6.0)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Non Compliance.	1(0.6)				
		non-compliance of study medication and holters.	1(0.6)				
		None compliance.	1(0.6)				
		not started study drug; pcp offered RX Losartan	1(0.6)				
		out of town & forgot to take study med with them	1(0.6)				
		Parent stopped drug. Did not contact study site	1(0.6)				
		Parents forgot to administer for 7 weeks.	1(0.6)				
		Patient decided not taking the study meds himself.	1(0.6)				
		PATIENT DID NOT CALL FOR REFILL	1(0.6)				
		patient non-compliance	1(0.6)				
		Patient noncompliant	2(1.2)				
		Patient refused to take her medications.	1(0.6)				
		per mom pt taking 75mg/day not 75BID as prescribed	1(0.6)				
		persistent nausea and vomiting	1(0.6)				
		persistent vomiting	1(0.6)				
		Pills accidentally discarded by family.	1(0.6)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Planned surgery	1(0.6)				
		possible allergic reaction per opthomologist	1(0.6)				
		prescription not filled in time	2(1.2)				
		Prescription not filled in timely manner	21(12.5)				
		Pt admitted non compliance at visit 3 for 3 months	1(0.6)				
		PT DID NOT CALL FOR REFILL	2(1.2)				
		Pt frequently changes cell #-unable to contact	6(3.6)				
		pt had no medication	1(0.6)				
		Pt not responsive to call-RX filled late	1(0.6)				
		pt not responsive, Rx not filled in time	1(0.6)				
		pt refused med bc thought it was uptitration	1(0.6)				
		Pt stopped taking medication.	1(0.6)				
		Pt taking drug incorrectly	1(0.6)				
		pt taking drug incorrectly- taking only 1 pill	1(0.6)				
		Pt. did not respond to calls or call for refill	5(3.0)				
		Ran out of medication.	1(0.6)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		ran out of study drug, took open label atenolol	1(0.6)				
		ran out-non compliance	1(0.6)				
		rash of unknown origin	1(0.6)				
		Refused pills after suspension. Now pills in food.	1(0.6)				
		Rx 003 Shipment lost in mail	1(0.6)				
		RX not refilled timely.	1(0.6)				
		See A200#4 and #5 (tiredness, sadness/depression)	1(0.6)				
		Severe fatigue and lethargy.	1(0.6)				
		Signs of depression.	1(0.6)				
		Skipped	14(8.3)				
		Study drug not shipped in time.	1(0.6)				
		study drug not shipped.	1(0.6)				
		Subject admitted to mental health facility-	1(0.6)				
		subject intermittently NC	1(0.6)				
		subject out of medication/ did not notify parent	1(0.6)				
		Subject ran out of drug & mom did not notify site	1(0.6)				

Marfan Data Codebook
A210: Study Drug Temporary Stop Form
(raw data)

DATE CREATED 13SEP18
Number of Observations: 168
Number of Variables: 12
Organization of file: Up to Seven Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Subject ran out of medication at home	1(0.6)				
		SUBJECT RAN OUT OF MEDICATION, UPS UNABLE TO	1(0.6)				
		surgery and hospital stay	1(0.6)				
		the patient was out of town without medicine.	1(0.6)				
		Transferred to Medical Center due to menorrhagia	1(0.6)				
		travels-not home for deliver	4(2.4)				
		Unable to contact subject.	1(0.6)				
		UNKNOWN	6(3.6)				
		viral illness with reflux and abdominal pain.	1(0.6)				
B4. Last dose of study drug prescribed	LASTDOSERX			152(16)	1.89(1.08)	1.40(1.15,2.90)	0.40-4.00
B5. Last daily dose of study drug taken	LASTDOSETKN			168(0)	79.36(63.45)	63.75(25.00,100.00)	1.00-250.00
Form Version	VER_ID	A	5(3.0)				
		B	163(97.0)				