

Data Set Name: longitudinal_ds.sas7bdat

Num	Variable	Type	Len	Informat	Label
1	maskid	Num	8	BEST32.	De-identified Subject ID
2	Visit	Char	37		Study visit
3	visitstutd	Num	8		Study visit day (days since enrollment)
4	AgeatV	Num	8		Age at visit (years)
5	UPCR	Num	8		Urine protein: creatinine ratio
6	eGFR	Num	8		eGFR (mL/min/1.73 m2): Children - Schwartz formula, Adults - CKD-EPI formula
7	SerumCreatinineComp	Num	8		Serum Creatinine (mg/dL)
8	Edema	Num	8		Any edema present
9	Edema_Anasarca	Num	8	8.	Anasarca edema
10	Edema_Facial	Num	8	8.	Facial edema
11	Edema_LowExtrem	Num	8	8.	Lower extremity edema
12	Edema_Sacral	Num	8	8.	Sacral edema
13	Height	Num	8	20.	Height (cm)
14	Weight	Num	8	20.	Weight (kg)
15	BMI	Num	8		BMI
16	BMIPCT	Num	8		BMI percentile; Calculated based on the U.S. population BMI distribution for each child's age and sex category
17	WeightStatus	Num	8		Weight status, based on BMI (BMI percentile in pediatric)
18	BP_SitSys	Num	8	3.	Sitting Systolic blood pressure
19	BP_SitDias	Num	8	3.	Sitting Diastolic blood pressure
20	SysPct	Num	8		Systolic percentile for toddler and infant; Calculated based on the U.S. population BP distribution for each child's age, sex and height category
21	DiasPct	Num	8		Diastolic percentile for toddler and infant; Calculated based on the U.S. population BP distribution for each child's age, sex and height category
22	HTNStatus	Num	8		Hypertensive status, based on JNC 7-8 Guidelines systolic/diastolic (systolic pct/diastolic pct in pediatric)
23	HTNStatus2	Num	8		Hypertensive status, based on 2017 ACC/AHA and AAP Guidelines systolic/diastolic (systolic pct/diastolic pct in pediatric)2017 ACC/AHA and AAP Guidelines
24	Hematocrit	Num	8		Hematocrit (percent)
25	Hemoglobin	Num	8		Hemoglobin (g/dL)
26	MCH	Num	8		MCH (pg)
27	MCHC	Num	8		MCHC (g/dL)
28	MCV	Num	8		MCV (fl)
29	Platelets	Num	8		Platelets (k/mm3)
30	WBC	Num	8		WBC (k/mm3)
31	A1c	Num	8		A1c (percent)
32	Albumin	Num	8		Albumin (g/dL)
33	AlkalinePhosphatase	Num	8		AlkalinePhosphate (iu/L)
34	ALT	Num	8		ALT (iu/L)
35	AST	Num	8		AST (iu/L)

Num	Variable	Type	Len	Informat	Label
36	Calcium	Num	8		Calcium (mg/dL)
37	Chloride	Num	8		Chloride (mmol/L)
38	CO2	Num	8		CO2 (mmol/L)
39	Glucose	Num	8		Glucose (mg/dL)
40	Magnesium	Num	8		Magnesium (mg/dL)
41	Phosphorus	Num	8		Phosphorus (mg/dL)
42	Potassium	Num	8		Potassium (mmol/L)
43	Sodium	Num	8		Sodium (mmol/L)
44	TotalBilirubin	Num	8		Total Bilirubin (mg/dL)
45	UreaNitrogen	Num	8		Urea Nitrogen (mg/dL)
46	CholesterolHDL_Cntrl	Num	8	BEST32.	HDL Cholesterol (mg/dL)
47	CholesterolLDL_Cntrl	Num	8		LDL Cholesterol (mg/dL)
48	CholesterolTotal_Cntrl	Num	8	BEST32.	Total Cholesterol (mg/dL)
49	Triglycerides_Cntrl	Num	8	BEST32.	Triglycerides (mg/dL)
50	UrineBlood	Num	8		Urinalysis: Hematuria
51	UrineProtein	Num	8		Urinalysis: Protein dipstick
52	ClinSymYN	Num	8	8.	Within the last 2 weeks, experienced any of the following clinical symptoms
53	ClinSym1_SB	Num	8	8.	Shortness of Breath
54	ClinSym2_Swell	Num	8	8.	Swelling
55	ClinSym3_Fever	Num	8	8.	Fever
56	ClinSym4_CPain	Num	8	8.	Chest pain
57	ClinSym5_FUrine	Num	8	8.	Foamy urine
58	ClinSym6_Diar	Num	8	8.	Diarrhea
59	ClinSym7_Naus	Num	8	8.	Nausea and/or vomiting
60	PROMIS_Adult_Anxiety	Num	8	BEST32.	PROMIS: Adult Anxiety Score
61	PROMIS_Adult_Fatigue	Num	8	BEST32.	PROMIS: Adult Fatigue Score
62	PROMIS_Adult_Mental	Num	8		PROMIS: Adult Mental Component Score
63	PROMIS_Adult_Physical	Num	8		PROMIS: Adult Physical Component Score
64	PROMIS_Adult_PhysicalFunction	Num	8	BEST32.	PROMIS: Adult Physical Functioning Score
65	PROMIS_Adult_Sleep	Num	8	BEST32.	PROMIS: Adult Sleep Disturbance Score
66	PROMIS_Proxy_Anxiety	Num	8	BEST32.	PROMIS: Parent Proxy Anxiety Score
67	PROMIS_Proxy_Depression	Num	8	BEST32.	PROMIS: Parent Proxy Depressive Symptoms Score
68	PROMIS_Proxy_Fatigue	Num	8	BEST32.	PROMIS: Parent Proxy Fatigue Score
69	PROMIS_Proxy_Global	Num	8	BEST32.	PROMIS: Parent Proxy Global Score
70	PROMIS_Proxy_Mobility	Num	8	BEST32.	PROMIS: Parent Proxy Mobility Score
71	PROMIS_Proxy_Stress	Num	8	BEST32.	PROMIS: Parent Proxy Stress Score
72	PROMIS_Ped_Anxiety	Num	8	BEST32.	PROMIS: Pediatric Anxiety Score
73	PROMIS_Ped_Depression	Num	8	BEST32.	PROMIS: Pediatric Depressive Symptoms Score
74	PROMIS_Ped_Fatigue	Num	8	BEST32.	PROMIS: Pediatric Fatigue Score

Num	Variable	Type	Len	Informat	Label
75	PROMIS_Ped_Global	Num	8	BEST32.	PROMIS: Pediatric Global Score
76	PROMIS_Ped_Mobility	Num	8	BEST32.	PROMIS: Pediatric Mobility Score
77	PROMIS_Ped_Stress	Num	8	BEST32.	PROMIS: Pediatric Stress Score
78	ImmunosuppressionV	Num	8		On immunosuppressive at visit
79	SteroidV	Num	8		On steroid at visit
80	CTXV	Num	8		On CTX at visit
81	CNIV	Num	8		On CNI at visit
82	RituxV	Num	8		On Rituximab at visit
83	MMFV	Num	8		On MMF at visit
84	OtherIStV	Num	8		On other immunosuppression therapy at visit
85	RAASblockV	Num	8		On RAAS blocker at visit
86	CoagPlateletV	Num	8		On anticoagulants at visit
87	DiureticV	Num	8		On diuretic at visit
88	CCBV	Num	8		On calcium channel blocker at visit
89	CentralV	Num	8		On central alpha agonist at visit
90	VasodilV	Num	8		On vasodilator at visit
91	BetaBlockV	Num	8		On beta-blocker at visit
92	AlphaBlockV	Num	8		On alpha-blocker at visit
93	ImmunosuppressionPrev	Num	8		On immunosuppressive prior to visit
94	SteroidPrev	Num	8		On steroid prior to visit
95	CTXPrev	Num	8		On CTX prior to visit
96	CNIPrev	Num	8		On CNI prior to visit
97	RituxPrev	Num	8		On Rituximab prior to visit
98	MMFPrev	Num	8		On MMF prior to visit
99	OtherIStPrev	Num	8		On other immunosuppression therapy prior to visit
100	RAASblockPrev	Num	8		On RAAS blocker prior to visit
101	CoagPlateletPrev	Num	8		On anticoagulants prior to visit
102	DiureticPrev	Num	8		On diuretic prior to visit
103	CCBPreV	Num	8		On calcium channel blocker prior to visit
104	CentralPreV	Num	8		On central alpha agonist prior to visit
105	VasodilPreV	Num	8		On vasodilator prior to visit
106	BetaBlockPreV	Num	8		On beta-blocker prior to visit
107	AlphaBlockPreV	Num	8		On alpha-blocker prior to visit

Data Set Name: patient_ds.sas7bdat

Num	Variable	Type	Len	Informat	Label
1	maskid	Num	8	BEST32.	De-identified Subject ID
2	PAT_AgeKDONset	Num	8		Age of onset of nephrotic syndrome or proteinuria (calculated using most recently reported date of onset)
3	PAT_AgeV2	Num	8		Age at baseline visit
4	PAT_Hispanic	Num	8		Ethnic Background
5	PAT_KDDurationMonths	Num	8		Duration (months) of kidney disease at enrollment
6	PAT_Ped	Num	8		Age less than 18 at time of baseline visit
7	PAT_Race	Num	8		Race
8	PAT_RaceBlack	Num	8		Race: Black/African American
9	PAT_Sex	Num	8		Patient sex from the demographic file [N1, N2]
10	PAT_Cohort	Num	8		Diagnostic cohort
11	CompRemSinceBL	Num	8		Patient in complete remission (UPCR<=0.3)after baseline visit (among active disease at baseline)
12	PartCompRemSinceBL	Num	8		Partial or complete remission after baseline visit (among active disease at baseline)
13	ESRDtxpDial	Num	8		End stage renal disease reached after baseline
14	ESRDorEGFR40	Num	8		End stage renal disease or 40% loss of eGFR reached after baseline
15	PAT_FUMonths	Num	8		Total follow-up months from enrollment to last visit
16	CanceratBL	Num	8		History of cancer at baseline
17	CADatBL	Num	8		History of coronary artery disease at baseline
18	DMatBL	Num	8		History of diabetes at baseline
19	HAatBL	Num	8		History of heart srrhythmia at baseline
20	HFatBL	Num	8		History of heart failure at baseline
21	HTNatBL	Num	8		History of hypertension at baseline
22	PVDatBL	Num	8		History peripheral vascular disease of at baseline
23	RheumatBL	Num	8		History of Rheumatologic disease at baseline
24	StrokeatBL	Num	8		History of stroke at baseline
25	TEatBL	Num	8		History of thromboembolic event at baseline
26	PAT_ChildKD_Ever	Num	8		Any biological children diagnosed with kidney disease
27	PAT_FamilyDM_Ever	Num	8		Family history of diabetes
28	PAT_FamilyESRD_Ever	Num	8		Family history of end stage renal disease
29	PAT_FamilyHTN_Ever	Num	8		Family history of hypertension
30	PAT_FamilyKD_Ever	Num	8		Family history of kidney disease
31	PAT_ParentKD_Ever	Num	8		Biological parent diagnosed with kidney disease
32	PAT_SibKD_Ever	Num	8		Any siblings with at least one common parent diagnosed with kidney disease
33	HeightPreKD	Num	8		Height prior to onset of kidney disease
34	WeightPreKD	Num	8		Weight prior to onset of kidney disease
35	BTerm	Num	8	8.	Birth Term
36	BirthWgt	Num	8		Birth weight (grams)
37	GestAge	Num	8		Gestational age weeks

Num	Variable	Type	Len	Informat	Label
38	BMultiple	Num	8	8.	Part of a multiple birth (twin, triplet, etc.)
39	FatherAge_Years	Num	8		Age of biological Father at time of birth - Years
40	FatherRace	Num	8		Father Racial Background
41	MotherAge_Years	Num	8		Age of biological mother at time of birth - Years
42	MotherRace	Num	8		Mother Racial Background
43	WorkStat	Num	8		Working status at baseline
44	StuStat	Num	8		Student status at baseline
45	NumHHAdults	Num	8		Number adults (18 and older) in same household at baseline
46	NumHHChild	Num	8		Number children (under 18) in the same household at baseline
47	AHHIncome	Num	8	8.	Gross Annual Household Income at baseline
48	FEdLevel	Num	8	8.	Highest grade/level of school completed by father (or second caregiver/guardian)
49	MEdLevel	Num	8	8.	Highest grade/level of school completed by mother (or primary caregiver/guardian)
50	EdLevel	Num	8	8.	Highest grade/level of school completed by participant
51	UPCR_V1	Num	8		Urine protein: creatinine ratio at screening/enrollment
52	RenalBxIndication	Num	8		Reason for Biopsy
53	RenalBxIndicationOther	Char	300		Reason for Biopsy Other Specify
54	number_of_risk_alleles	Num	8	BEST32.	Number of APOL1 risk alleles