**Supplemental Table 1. Summary of data collection and variable definition and categorization used for this study**

|  |  |  |  |
| --- | --- | --- | --- |
| Demographics | | |  |
|  | Age in years | | At enrollment |
|  | Sex | |  |
|  | Race-Ethnicity | | Self-reported at enrollment; race and ethnicity collected separately, placed into combined categories. Patients with any other race or ethnicity were excluded |
|  |  | White: White race, not Hispanic ethnicity |
|  |  | Black: Black race and any ethnicity |
|  |  | Asian: Asian race and any ethnicity |
|  |  | Hispanic: White race and Hispanic ethnicity |
|  |  | |  |
| Socioeconomic Status | | |  |
|  | Country of residence | | Based on enrollment site, categorized: USA, Canada, Italy, Poland |
|  | Participant or Parent completed level of education | | College Education defined as 2 year associates degree/certificate or higher |
|  | Insurance type | |  |
|  |  | Private |  |
|  |  | Public | Medicare, Medicaid, VA for US participants;  Other government provided insurance for non-US participants |
|  |  | Other | Self-identified by participant |
|  |  | None |  |
|  | Employment or student status | | Combined into a single variable with mutually exclusive categories. |
|  |  | Employed and not a student |  |
|  |  | Employed and a student |  |
|  |  | Unemployed and not a student |  |
|  |  | Unemployed and a student |  |
|  |  | On medical leave/disability |  |
|  |  | Other | Working in the home, retired |
|  |  | |  |
| Chronic disease burden | | |  |
|  | disease type | | Confirmed on biopsy, categorized: MCD, FSGS, MN, IgAN/IgAV |
|  | Disease duration in months | | Months from initial diagnostic kidney biopsy to enrollment |
|  | Hypertension at enrollment | | Based on measured blood pressure at enrollment, categorized: normal (Systolic BP<=120 and Diastolic BP <=80 for Adults, Systolic and Diastolic percentile <=90th for Pediatrics), pre-hypertension (Systolic BP > 120 or Diastolic BP > 80 for Adults, Systolic or Diastolic percentile between 90th and 95th for Pediatrics), or hypertension (Systolic BP>140 or Diastolic BP > 90, or Systolic or Diastolic percentile > 95th for Pediatrics) 20,21 |
|  | Weight at enrollment | | Based on BMI at enrollment, categorized: normal or underweight (BMI < 25), overweight (BMI 25 to <30), or obese (BMI 30 or greater) |
|  | Family history of kidney disease | | Self-reported by patient at enrollment including kidney failure |
|  |  | |  |
| Current disease severity/activity | | |  |
|  | Edema | | Self-reported presence and severity rated from 0 (absent) to 5 (worst imaginable), categorized: less than moderate (≤2) vs moderate (≥3) or greater |
|  | Kidney related laboratory measures | |  |
|  |  | Calculated estimated glomerular filtration rate (eGFR) in mL/min/1.73m2 | For adults: Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) equation for adults29  For children ≤ 18 years: modified Chronic Kidney Disease in Children (CKiD-Schwartz) formula30  For adolescents 18-26 years: an average of the 2 formulas31 |
|  |  | Urine protein-to-creatinine ration (uPCR) in g/g | Measured from a 24 hour urine collection, or, if unavailable, a spot sample |
|  |  | Serum albumin in g/dL | Measured at time of enrollment |
|  | Requirement for glucocorticoids | | Self-reported use of any glucocorticoids at enrollment |
|  | Requirement for other immunosuppression | | Self-reported use of Abatacept, Belatecept, ACTH, antimetabolite, cyclophosphamide, chlorambucil, calcineurin inhibitor, levamisole, mycophenolic acid, or rituximab at enrollment |

**Supplemental Table 2: Demographic, socioeconomic, and clinical characteristics at enrollment for cohort with complete data: adults (n=708)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | | **White (n=465)** | **Black (n=111)** | **Asian (n=66)** | **Hispanic (n=66)** | **P-value** |
| Age | | 50 (36-63) | 46 (34-57) | 43 (35-51) | 40 (35-50) | **<0.001** |
| Male | | 282 (61) | 45 (41) | 32 (48) | 39 (59) | **<0.001** |
| Country of residence | |  |  |  |  | **0.001** |
|  | USA | 385 (83) | 105 (95) | 47 (71) |  |  |
|  | Canada | 66 (14) | 6 (5) | 19 (29) |  |  |
|  | Italy | 1 (0) | 0 (0) | 0 (0) |  |  |
|  | Poland | 13 (3) | 0 (0) | 0 (0) |  |  |
| Insurance status at enrollment | |  |  |  |  | **<0.001** |
|  | Private | 351 (75) | 63 (57) | 48 (73) |  |  |
|  | Public | 96 (21) | 35 (32) | 12 (18) |  |  |
|  | Other | 13 (3) | 9 (8) | 6 (9) |  |  |
|  | None | 5 (1) | 4 (4) | 0 (0) |  |  |
| College education | | 230 (49) | 32 (29) | 49 (74) | 22 (33) | **<0.001** |
| Current Student/Employment Status | |  |  |  |  | 0.1 |
|  | Employed, not a student | 281 (60) | 70 (63) | 48 (73) |  |  |
|  | Employed and a student | 30 (6) | 7 (6) | 5 (8) |  |  |
|  | Student, not employed | 8 (2) | 2 (2) | 2 (3) |  |  |
|  | Medical leave or disabled | 33 (7) | 9 (8) | 0 (0) |  |  |
|  | Unemployed | 23 (5) | 12 (11) | 2 (3) |  |  |
|  | Other | 90 (19) | 11 (10) | 9 (14) |  |  |
| Disease type | |  |  |  |  | **<0.001** |
|  | MCD | 70 (15) | 14 (13) | 12 (18) |  |  |
|  | FSGS | 111 (24) | 50 (45) | 7 (11) |  |  |
|  | MN | 165 (35) | 39 (35) | 18 (27) |  |  |
|  | IgAN/IgAV | 119 (26) | 8 (7) | 29 (44) |  |  |
| Family history of kidney disease | | 140 (30) | 48 (43) | 22 (33) | 20 (30) | 0.07 |
| Disease duration, in months | | 11.2 (4.3-28.4) | 11.5 (5.3-35.1) | 15.0 (4.3-34.9) | 10.9 (3.6-32.1) | 0.8 |
| Hypertension status at enrollment | |  |  |  |  | **<0.001** |
|  | Normal | 128 (28) | 31 (28) | 32 (48) |  |  |
|  | Pre-hypertensive | 212 (46) | 38 (34) | 25 (38) |  |  |
|  | Hypertensive | 125 (27) | 42 (38) | 9 (14) |  |  |
| Weight status at enrollment | |  |  |  |  | **<0.001** |
|  | Normal/Underweight | 120 (26) | 22 (20) | 35 (53) |  |  |
|  | Overweight | 161 (35) | 22 (20) | 25 (38) |  |  |
|  | Obese | 184 (40) | 67 (60) | 6 (9) |  |  |
| Moderate or greater edema at enrollment | | 152 (33) | 55 (50) | 17 (26) | 22 (33) | **0.003** |
| Urine protein-to-creatinine ratio (g/g) | | 1.78 (0.46-4.49) | 2.44 (0.82-6.24) | 1.62 (0.57-3.30) | 1.61 (0.54-3.61) | 0.1 |
| eGFR (mL/min/1.73m2) | | 65 (42-91) | 63 (42-94) | 81 (45-103) | 65 (37-96) | 0.2 |
| Serum Albumin (g/dL) | | 3.8 (3.1-4.2) | 3.5 (2.6-3.9) | 3.8 (3.4-4.2) | 3.9 (3.3-4.1) | **<0.001** |
| Current glucocorticoids | | 163 (35) | 37 (33) | 19 (29) | 16 (24) | 0.3 |
| Current other immunosuppression | | 148 (32) | 39 (35) | 22 (33) | 16 (24) | 0.5 |
| **BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.  All values represent n (%) or median (IQR) unless otherwise indicated  MCD, minimal change disease; FSGS, focal segmental glomerulosclerosis; MN, membranous nephropathy; IgAN, IgA nephropathy; IgAV, IgA vasculitis; eGFR, estimated glomerular filtration rate | | | | | | |
|  | | | | | | |

**Supplemental Table 3: Demographic, socioeconomic, and clinical characteristics at enrollment for cohort with complete data: children (n=386)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | **White (n=261)** | **Black (n=69)** | **Asian (n=21)** | **Hispanic (n=35)** | **P-value** |
| Age | | 12 (8-15) | 14 (9-16) | 10 (7-13) | 11 (7-15) | 0.1 |
| Male | | 155 (59) | 34 (49) | 12 (57) | 17 (49) | 0.4 |
| Country of residence | |  |  |  |  | **<0.001** |
|  | USA | 220 (84) | 67 (97) | 14 (67) | 31 (89) |  |
|  | Canada | 5 (2) | 2 (3) | 6 (29) | 1 (3) |  |
|  | Italy | 36 (14) | 0 (0) | 1 (5) | 3 (9) |  |
| Insurance status at enrollment | |  |  |  |  | 0.01 |
|  | Private | 154 (59) | 24 (35) | 9 (43) | 11 (31) |  |
|  | Public | 100 (38) | 43 (62) | 11 (52) | 22 (63) |  |
|  | Other | 5 (2) | 1 (1) | 1 (5) | 2 (6) |  |
|  | None | 2 (1) | 1 (1) | 0 (0) | 0 (0) |  |
| College education | |  |  |  |  |  |
|  | Mother | 107 (41) | 13 (19) | 9 (43) | 3 (9) | **<0.001** |
|  | Father | 91 (37) | 12 (20) | 11 (52) | 3 (9) | **<0.001** |
|  | Either parent | 118 (45) | 21 (30) | 12 (57) | 4 (11) | **<0.001** |
| Disease type | |  |  |  |  | **<0.001** |
|  | MCD | 95 (36) | 31 (45) | 10 (48) | 15 (43) |  |
|  | FSGS | 46 (18) | 31 (45) | 4 (19) | 5 (14) |  |
|  | MN | 11 (4) | 3 (4) | 0 (0) | 3 (9) |  |
|  | IgAN/IgAV | 109 (42) | 4 (6) | 7 (33) | 12 (34) |  |
| Family history of kidney disease | | 67 (26) | 27 (39) | 8 (38) | 12 (34) | 0.1 |
| Disease duration, in months | | 12.2 (4.2-32.4) | 10.8 (2.6-41.5) | 22.7 (6.5-52.3) | 13.30 (3.0-34.3) | 0.8 |
| Hypertension status at enrollment | |  |  |  |  | 0.3 |
|  | Normal | 170 (65) | 38 (55) | 15 (71) | 21 (60) |  |
|  | Pre-hypertensive | 36 (14) | 16 (23) | 1 (5) | 4 (11) |  |
|  | Hypertensive | 55 (21) | 15 (22) | 5 (24) | 10 (29) |  |
| Weight status at enrollment | |  |  |  |  | 0.3 |
|  | Normal/Underweight | 134 (51) | 28 (41) | 10 (48) | 14 (40) |  |
|  | Overweight | 56 (21) | 12 (17) | 4 (19) | 6 (17) |  |
|  | Obese | 71 (27) | 29 (42) | 7 (33) | 15 (43) |  |
| Moderate or greater edema at enrollment | | 32 (12) | 17 (25) | 3 (14) | 8 (23) | 0.05 |
| Urine protein-to-creatinine ratio (g/g) | | 0.31 (0.10-1.83) | 0.97 (0.14-2.89) | 0.38 (0.13-2.54) | 1.21 (0.13-5.62) | 0.1 |
| eGFR (mL/min/1.73m2) | | 101 (84-120) | 92 (70-113) | 116 (105-142) | 119 (103-141) | **<0.001** |
| Serum albumin (g/dL) | | 3.8 (3.20-4.2) | 3.5 (2.9-4.1) | 4.0 (3.6-4.3) | 3.9 (2.7-4.3) | 0.08 |
| Current glucocorticoids | | 116 (44) | 31 (45) | 10 (48) | 17 (49) | 1.0 |
| Current other immunosuppression | | 135 (52) | 29 (42) | 11 (52) | 22 (63) | 0.2 |
| **BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.  All values represent n (%) or median (IQR) unless otherwise indicated  MCD, minimal change disease; FSGS, focal segmental glomerulosclerosis; MN, membranous nephropathy; IgAN, IgA nephropathy; IgAV, IgA vasculitis; eGFR, estimated glomerular filtration rate | | | | | | |
|  | | | | | | |

**Supplemental Table 4. Unadjusted Health Related Quality of Life (HRQOL) measures in adults enrolled in CureGN (n=1,379)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | **White (n=884)** | **Black (n=226)** | **Asian (n=146)** | **Hispanic (n=123)** | **P-value** |
| **Missed work or school due to kidney disease in the last 4 months?** | *Number of days missed, Median (IQR)\** | 0 (0,0) | 0 (0,3) | 0 (0,0) | 0 (0,0) | 0.06 |
| *Missed any days, n (%)\** | 130/575 (23) | 42/142 (30) | 18/109 (17) | 13/80 (16) | 0.04 |
| **PROMIS Global Physical health** | *Score, median (IQR)* | 48.0 (41.4,54.7) | 44.1 (36.9,50.7) | 48.0 (42.0,54.7) | 48.2 (40.3,54.7) | **<0.001** |
| *Score < 47, n (%)* | 411 (47) | 135 (61) | 62 (44) | 57 (48) | 0.002 |
| **PROMIS Global Mental health** | *Score, median (IQR)* | 50.9 (44.3,55.6) | 48.15 (40.3,55.2) | 50.9 (43.3,56.7) | 50.9 (44.1,55.4) | 0.05 |
| *Score < 47, n (%)* | 329 (38) | 103 (46) | 58 (41) | 44 (37) | 0.11 |
| **PROMIS Anxiety** | *Score, median (IQR)* | 49.3 (40.5,55.9) | 49.3 (40.5,55.9) | 49.3 (40.5,55.9) | 55.9 (49.3,55.9) | 0.6 |
| *Score > 53, n (%)* | 402 (46) | 101 (47) | 68 (49) | 63 (53) | 0.5 |
| **PROMIS Fatigue** | *Score, median (IQR)* | 51.1 (43.9,57.7) | 53.8 (46.9,61.3) | 49.4 (43.3,56.7) | 48.5 (42.6,57.7) | **0.002** |
| *Score > 53, n (%)* | 358 (41) | 112 (51) | 58 (41) | 41 (34) | 0.01 |
| **PROMIS Sleep Disturbance** | *Score, median (IQR)* | 52.9 (42.3,59.4) | 52.9 (42.3,59.4) | 52.9 (42.3,59.4) | 52.9 (42.3,59.4) | 0.4 |
| *Score > 53, n (%)* | 238 (28) | 80 (37) | 36 (25) | 36 (30) | 0.04 |

**Legend.** Shown are the unadjusted adult patient reported health outcomes, presented by racial/ethnic group.

\*Asterisk denotes the analysis is restricted to patients who are employed or in school full or part time.

**BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.

PROMIS, patient reported outcomes measurement information system.

Missed work due to kidney disease in the last 4 months has a 7% missing rate, the remaining HRQOL measures are missing at less than 3%. There are no significant differences in missingness across racial/ethnic groups.

**Supplemental Table 5. Unadjusted Health Related Quality of Life (HRQOL) measures in children enrolled in CureGN (n=785)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | | **White (n=517)** | **Black (n=146)** | **Asian (n=45)** | **Hispanic (n=77)** | **P-value** |
| **Missed school due to kidney disease, in the last 4 months?** | *Number of days missed, Median (IQR)* | 0 (0,5) | 2 (0,7) | 0 (0,0) | 1 (0,5) | 0.06 |
| *Missed any days, n (%)* | 199 (38.5) | 66 (45.2) | 13 (28.9) | 34 (44.2) | 0.1 |
| **Parent or guardian missed work or school due to kidney disease, in the last 4 months?** | *Number of days missed, Median (IQR)* | 0 (0,4) | 0 (0,3) | 0 (0,0) | 0 (0,4) | 0.04 |
| *Missed any days, n (%)* | 194 (40.2) | 49 (37.1) | 8 (18.6) | 28 (39.4) | 0.05 |
| **PROMIS Global Health scale** | *Score, median (IQR)* | 48.4 (41.0,53.8) | 47.1 (39.0,53.4) | 46.8 (41.2,56.4) | 46.2 (39.5,53.5) | 0.3 |
| *Score < 47, n (%)* | 207 (42.9) | 66 (50) | 21 (51.2) | 39 (54.2) | 0.2 |
| **PROMIS Anxiety\*** | *Score, median (IQR)* | 48.6 (41.4,54.6) | 48.6 (41.4,54.6) | 41.4 (41.4,48.6) | 41.4 (41.4,49.3) | 0.03 |
| *Score > 53, n (%)* | 104 (31.3) | 29 (28.4) | 4 (15.4) | 11 (24.4) | 0.30 |
| **PROMIS Fatigue** | *Score, median (IQR)* | 43.4 (34.3,52.9) | 46.4 (34.4,53.9) | 43.1 (30.8,50.7) | 45.4 (34.1,56.9) | 0.3 |
| *Score > 53, n (%)* | 117 (24.3) | 39 (29.8) | 7 (18.4) | 24 (34.3) | 0.2 |
| **PROMIS Mobility** | *Score, median (IQR)* | 56.3 (45.4,57.8) | 56.3 (43.0,57.8) | 56.3 (45.6,57.8) | 56.3 (43.1,57.8) | 0.3 |
| *Score < 47, n (%)* | 140 (29.3) | 43 (33.3) | 11 (28.2) | 26 (36.6) | 0.5 |
| **Legend.** Shown are the unadjusted pediatric patient or parent reported health outcomes, presented by racial/ethnic group.  \* Asterisk denotes analysis restricted to subjects ≥8 years of age (n=505).  **BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.  PROMIS, patient reported outcomes measurement information system.  All HRQOL measures are missing between 6-8%. There are no significant differences in missingness across racial/ethnic groups. | | | | | | |

**Supplemental Table 6: Differences in demographic, socioeconomic, and clinical characteristics at enrollment for cohort with missing data versus cohort with full data: adults**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | | Missing Data Cohort (n=641) | Full Data Cohort (n=708) | P-value |
| Race | |  |  | 0.3 |
|  | White | 412 (64%) | 465 (66%) |  |
|  | Black | 106 (17%) | 111 (16%) |  |
|  | Asian | 76 (12%) | 66 (9%) |  |
|  | Hispanic | 47 (7%) | 66 (9%) |  |
| Male | | 367 (57%) | 398 (56%) | 0.7 |
| Age |  | 46 (31-60) | 47 (35-60) | 0.1 |
| Country of residence | |  |  | **0.002** |
|  | USA | 553 (86%) | 596 (84%) |  |
|  | Canada | 59 (9%) | 98 (14%) |  |
|  | Italy | 7 (1%) | 1 (0%) |  |
|  | Poland | 22 (3%) | 13 (2%) |  |
| Insurance status at enrollment | |  |  | 0.01 |
|  | Private | 456 (74%) | 493 (69%) |  |
|  | Public | 129 (21%) | 154 (22%) |  |
|  | Other | 27 (4%) | 38 (5%) |  |
|  | None | 5 (1%) | 23 (3%) |  |
| College education | | 273 (43%) | 333 (47%) | 0.1 |
| Current Student/Employment Status | |  |  | 0.4 |
|  | Employed, not a student | 347 (60%) | 439 (62%) |  |
|  | Employed and a student | 44 (8%) | 46 (7%) |  |
|  | Student, not employed | 16 (3%) | 14 (2%) |  |
|  | Medical leave or disabled | 28 (5%) | 48 (7%) |  |
|  | Unemployed | 29 (5%) | 43 (6%) |  |
|  | Other | 112 (19%) | 118 (17%) |  |
| Disease Type | |  |  | 0.7 |
|  | MCD | 100 (16%) | 100 (14%) |  |
|  | FSGS | 167 (26%) | 190 (27%) |  |
|  | MN | 199 (31%) | 235 (33%) |  |
|  | IgAN/IgAV | 175 (27%) | 183 (26%) |  |
| Family history of kidney disease | | 207 (34%) | 230 (32%) | 0.5 |
| Disease duration, in months | | 20.9 (6.8-46.0) | 11.3 (4.3-30.2) | **<0.0001** |
| Hypertension status at enrollment | |  |  | **0.008** |
|  | Normal | 226 (39%) | 219 (31%) |  |
|  | Pre-hypertensive | 219 (38%) | 299 (42%) |  |
|  | Hypertensive | 132 (23%) | 190 (27%) |  |
| Weight status at enrollment | |  |  | 0.2 |
|  | Normal/Underweight | 191 (32%) | 195 (28%) |  |
|  | Overweight | 194 (32%) | 231 (33%) |  |
|  | Obese | 218 (36%) | 282 (40%) |  |
| Moderate or greater edema at enrollment | | 130 (23%) | 246 (35%) | **<0.0001** |
| Urine protein-to-creatinine ratio (g/g) | | 1.29 (0.28-4.03) | 1.78 (0.51-4.52) | **0.006** |
| eGFR (mL/min/1.73m2) | | 72 (42-94) | 66 (42-93) | 0.3 |
| Serum Albumin (g/dL) | | 3.8 (3.1-4.2) | 3.7 (3.0-4.1) | 0.4 |
| Current glucocorticoids | | 149 (23%) | 235 (33%) | **<0.0001** |
| Current other immunosuppression | | 163 (25%) | 225 (32%) | 0.01 |
| **BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.  All values represent n (%) or median (IQR) unless otherwise indicated  MCD, minimal change disease; FSGS, focal segmental glomerulosclerosis; MN, membranous nephropathy; IgAN, IgA nephropathy; IgAV, IgA vasculitis; eGFR, estimated glomerular filtration rate | | | | |

**Supplemental Table 7: Differences in demographic, socioeconomic, and clinical characteristics at enrollment for cohort with missing data versus cohort with full data: children**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Missing Data Cohort (n=372) | Full Data Cohort (n=386) | P-value |
| Race |  |  |  | 0.9 |
|  | White | 243 (65%) | 261 (68%) |  |
|  | Black | 68 (18%) | 69 (18%) |  |
|  | Asian | 24 (6%) | 21 (5%) |  |
|  | Hispanic | 37 (10%) | 35 (9%) |  |
| Age | | 11 (7-14) | 12 (7-15) | 0.02 |
| Male | | 221 (59%) | 218 (56%) | 0.4 |
| Country of residence | |  |  | 0.2 |
|  | USA | 335 (90%) | 332 (86%) |  |
|  | Canada | 9 (2%) | 14 (4%) |  |
|  | Italy | 28 (7%) | 40 (10%) |  |
| Insurance status at enrollment | |  |  | 0.6 |
|  | Private | 172 (52%) | 198 (51%) |  |
|  | Public | 141 (43%) | 176 (46%) |  |
|  | Other | 11 (3%) | 9 (2%) |  |
|  | None | 5 (2%) | 3 (1%) |  |
| Either parent college educated | | 117 (36%) | 155 (40%) | 0.3 |
| Disease type | |  |  | 0.6 |
|  | MCD | 145 (39%) | 151 (39%) |  |
|  | FSGS | 87 (23%) | 86 (22%) |  |
|  | MN | 23 (6%) | 17 (4%) |  |
|  | IgAN/IgAV | 117 (31%) | 132 (34%) |  |
| Family history of kidney disease | | 107 (31%) | 114 (30%) | 0.8 |
| Disease duration, in months | | 17.0 (6.2-39.5) | 12.1 (3.7-34.6) | 0.01 |
| Hypertension status at enrollment | |  |  | 0.6 |
|  | Normal | 213 (63% | 244 (63%) |  |
|  | Pre-hypertensive | 42 (13%) | 57 (8%) |  |
|  | Hypertensive | 81 (24%) | 85 (22%) |  |
| Weight status at enrollment | |  |  | 1.0 |
|  | Normal/Underweight | 179 (49%) | 186 (48%) |  |
|  | Overweight | 73 (20%) | 78 (20%) |  |
|  | Obese | 111 (31%) | 122 (32%) |  |
| Moderate or greater edema at enrollment | | 33 (12%) | 60 (16%) | 0.2 |
| Urine protein-to-creatinine ratio (g/g) | | 0.50 (0.13-2.04) | 0.38 (0.11-2.43) | 0.4 |
| eGFR (mL/min/1.73m2) | | 101 (86-125) | 103 (83-120) | 0.8 |
| Serum Albumin (g/dL) | | 3.8 (2.8-4.2) | 3.8 (3.1-4.2) | 0.3 |
| Current glucocorticoids | | 124 (33%) | 174 (45%) | **0.001** |
| Current other immunosuppression | | 173 (47%) | 197 (51%) | 0.2 |
| **BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.  All values represent n (%) or median (IQR) unless otherwise indicated  MCD: minimal change disease, FSGS: focal segmental glomerulosclerosis, MN: membranous nephropathy, IgAN, IgA nephropathy; IgAV, IgA vasculitis; eGFR, estimated glomerular filtration rate | | | | |

**Supplemental Table 8. Variables significantly associated with Health Related Quality of Life (HRQOL) in the final, fully adjusted models**: **US adults only (n=596\*)**

|  | **Any Missed Work or School OR (95% CI)\*\*** | **P-Value** | **PROMIS Physical Health**  **Beta (95% CI)**  Higher=Better | **P-Value** | **PROMIS Mental Health**  **Beta (95% CI)**  Higher=Better | **P-Value** | **PROMIS Anxiety**  **Beta (95% CI)**  Lower=Better | **P-Value** | **PROMIS  Fatigue**  **Beta (95% CI)**  Lower=Better | **P-Value** | **PROMIS Sleep Disturbance**  **Beta (95% CI)**  Lower=Better | **P-Value** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Race (ref=White) |  | 0.3 |  | 0.4 |  | 0.7 |  | 0.6 |  | 0.02 |  | 0.9 |
| Black | 1.10 (0.52,2.3) | 0.8 | 0.37 (-1.58,2.31) | 0.7 | 0.22 (-1.82,2.27) | 0.8 | 0.64 (-1.16,2.44) | 0.5 | -0.91 (-3,1.19) | 0.4 | -0.37 (-2.28,1.54) | 0.7 |
| Asian | 0.60 (0.2,1.83) | 0.4 | -1.02 (-3.59,1.56) | 0.4 | -0.49 (-3.2,2.21) | 0.7 | 1.52 (-0.82,3.86) | 0.2 | 0.26 (-2.49,3.00) | 0.9 | 0.49 (-2.00,2.99) | 0.7 |
| Hispanic | 0.36 (0.12,1.11) | 0.07 | 1.91 (-0.59,4.41) | 0.1 | 1.44 (-1.18,4.07) | 0.3 | 0.48 (-1.82,2.78) | 0.7 | **-4.18 (-6.85,-1.50)** | **0.002** | -0.68 (-3.10,1.75) | 0.6 |
| Age (per 10 year increase) | **0.74 (0.59,0.91)** | **0.005** |  |  |  |  |  |  |  |  |  |  |
| Female | 0.52 (0.29,0.93) | 0.03 | **-1.80 (-3.19,-0.40)** | **0.01** |  |  | **1.64 (0.36,2.93)** | **0.01** | **2.36 (0.86,3.85)** | **0.002** |  |  |
| Employment/Student Status (ref=Working, non-student) |  |  |  | **0.0002** |  | **<.0001** |  |  |  |  |  | **0.02** |
| Employed and Student |  |  | -5.61 (-11.05,-0.18) | 0.04 | -6.29 (-12,-0.58) | 0.03 |  |  |  |  | 0.50 (-4.75,5.75) | 0.9 |
| Student, no employment |  |  | -1.07 (-3.91,1.78) | 0.5 | -1.64 (-4.62,1.34) | 0.3 |  |  |  |  | -0.90 (-3.65,1.85) | 0.5 |
| Medical Leave |  |  | **-6.42 (-10.25,-2.59)** | **0.001** | **-7.18 (-11.2,-3.16)** | **0.0005** |  |  |  |  | 3.06 (-0.68,6.80) | 0.1 |
| Unemployed |  |  | **-5.69 (-9.66,-1.73)** | **0.005** | **-6.88 (-11.05,-2.71)** | **0.001** |  |  |  |  | 2.65 (-1.19,6.49) | 0.2 |
| Other |  |  | -2.29 (-5.88,1.3) | 0.2 | -3.05 (-6.82,0.72) | 0.1 |  |  |  |  | -1.42 (-4.89,2.05) | 0.4 |
| College Educated |  |  | **2.14 (0.82,3.45)** | **0.001** |  |  |  |  |  |  |  |  |
| Obesity Status (ref=Normal/Underweight) |  |  |  | **0.0002** |  |  |  |  |  |  |  |  |
| Overweight |  |  | -1.43 (-3.17,0.32) | 0.1 |  |  |  |  |  |  |  |  |
| Obese |  |  | **-3.6 (-5.32,-1.89)** | **<.0001** |  |  |  |  |  |  |  |  |
| Diagnosis Group (ref=IgAV/IgAN) |  |  |  | 0.04 |  |  |  |  |  |  |  |  |
| MCD |  |  | -1.88 (-4.34,0.57) | 0.1 |  |  |  |  |  |  |  |  |
| MN |  |  | 1.3 (-0.89,3.49) | 0.2 |  |  |  |  |  |  |  |  |
| FSGS |  |  | -0.56 (-2.54,1.41) | 0.6 |  |  |  |  |  |  |  |  |
| Moderate or greater edema | **3.74 (2.1,6.69)** | **<.0001** | **-6.96 (-8.46,-5.47)** | **<.0001** | **-4.40 (-5.97,-2.83)** | **<.0001** | **3.67 (2.30,5.04)** | **<.0001** | **6.46 (4.86,8.06)** | **<.0001** | **3.29 (1.83,4.75)** | **<.0001** |
| uPCR (per unit increase) | 1.10 (1.02,1.19) | 0.01 | **-0.23 (-0.38,-0.08)** | **0.002** |  |  |  |  | **0.25 (0.09,0.41)** | **0.003** | 0.06 (-0.08,0.21) | 0.4 |
| eGFR (per unit increase) | 0.99 (0.98,1) | 0.04 |  |  | 0.03 (0.00,0.06) | 0.04 |  |  |  |  |  |  |
| On glucocorticoid | **2.65 (1.51,4.68)** | **0.0007** |  |  |  |  |  |  |  |  | 1.64 (0.16,3.11) | 0.03 |
| **Legend**. Shown are variables significantly associated with health-related quality of life for adults in the final, fully adjusted models. Note that associations with race/ethnicity are reported even when not statistically significant.  \* Only patients with complete data for all variables included for adjusted analyses.  \*\*Among participants either in school or employed (n=844)  **BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.  uPCR, urine protein-to-creatinine ratio (g/g); eGFR, estimated glomerular filtration rate | | | | | | | | | | | | |

**Supplemental Table 9. Variables significantly associated with Health Related Quality of Life (HRQOL) in the final, fully adjusted models: US children only (n=332\*)**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Any Missed School OR (95% CI)** | **P-Value** | **Parents: Any Missed Work or School OR (95% CI)** | **P-Value** | **PROMIS Global Health**  **Beta (95% CI)**  Higher=Better | **P-Value** | **PROMIS Anxiety Beta (95% CI)\*\***  Lower=Better | **P-Value** | **PROMIS Fatigue Beta (95% CI)**  Lower=Better | **P-Value** | **PROMIS Mobility Beta (95% CI)**  Higher=Better | **P-Value** |
| Race (ref=White) |  | 0.8 |  | 0.9 |  | 0.1 |  | 0.3 |  | 0.01 |  | 0.8 |
| Black | 1.00 (0.49,2.06) | 1.0 | 0.85 (0.39,1.82) | 0.7 | 3.15 (0.39,5.92) | 0.03 | -1.84 (-4.12,0.45) | 0.1 | -3.93 (-7.32,-0.55) | 0.02 | 1.24 (-1.16,3.63) | 0.3 |
| Asian | 1.58 (0.45,5.51) | 0.5 | 0.58 (0.15,2.18) | 0.4 | -0.36 (-5.39,4.66) | 0.9 | -1.93 (-6.12,2.27) | 0.4 | -1.77 (-7.90,4.36) | 0.6 | 0.09 (-4.23,4.41) | 1.0 |
| Hispanic | 1.35 (0.54,3.35) | 0.5 | 0.90 (0.36,2.28) | 0.8 | -1.08 (-4.46,2.31) | 0.5 | -1.26 (-4.33,1.81) | 0.4 | 4.25 (0.06,8.43) | 0.05 | -0.15 (-3.06,2.76) | 0.9 |
| Age (per 10 year increase) |  |  |  |  |  |  |  |  | -4.32 (-7.62,-1.01) | 0.01 |  |  |
| Female |  |  |  |  |  |  | 1.80 (0.17,3.43) | 0.03 |  |  |  |  |
| Insurance (ref=Private) |  |  |  |  |  | 0.04 |  |  |  |  |  |  |
| Public |  |  |  |  | -1.83 (-4.20,0.54) | 0.1 |  |  |  |  |  |  |
| Other |  |  |  |  | 3.58 (-3.01,10.16) | 0.3 |  |  |  |  |  |  |
| No Insurance |  |  |  |  | 9.40 (-0.61,19.42) | 0.07 |  |  |  |  |  |  |
| Disease group (ref=IgAN/IgAV) |  |  |  | 0.02 |  |  |  |  |  |  |  |  |
| MCD |  |  | 1.22 (0.61,2.43) | 0.6 |  |  |  |  |  |  |  |  |
| MN |  |  | 2.13 (0.46,9.79) | 0.3 |  |  |  |  |  |  |  |  |
| FSGS |  |  | 0.41 (0.19,0.89) | 0.02 |  |  |  |  |  |  |  |  |
| Duration of disease (per year increase) |  |  | **0.73 (0.62,0.86)** | **0.0001** |  |  |  |  |  |  | -0.46 (-0.90,-0.02) | 0.04 |
| Weight status (ref=Normal/Underweight) |  |  |  |  |  | **0.003** |  |  |  |  |  | **0.002** |
| Overweight |  |  |  |  | 0.02 (-2.54,2.57) | 1.0 |  |  |  |  | -1.42 (-3.62,0.78) | 0.2 |
| Obese |  |  |  |  | **-3.74 (-6,-1.48)** | **0.001** |  |  |  |  | **-3.52 (-5.46,-1.58)** | **0.0004** |
| Family history of kidney disease | 1.83 (1.04,3.20) | 0.04 |  |  |  |  |  |  |  |  |  |  |
| Moderate or greater edema |  |  |  |  | **-4.80 (-7.58,-2.03)** | **0.0007** | 2.86 (0.40,5.32) | 0.02 | **9.03 (5.65,12.41)** | **<.0001** | **-5.54 (-7.92,-3.16)** | **<.0001** |
| uPCR (per unit increase) |  |  |  |  |  |  |  |  |  |  | -0.21 (-0.38,-0.05) | 0.01 |
| eGFR (per unit increase) |  |  |  |  |  |  |  |  | -0.05 (-0.08,-0.01) | 0.02 |  |  |
| Serum albumin (per unit increase) |  |  |  |  | 1.29 (0.06,2.52) | 0.04 |  |  |  |  |  |  |
| **Legend**. Shown are variables significantly associated with health-related quality of life for children in the final, fully adjusted models. Note that associations with race/ethnicity are reported even when not statistically significant.  \* Only patients with complete data for all variables included for adjusted analyses.  \*\* Administered only to children age 8 or older  **BOLD** p-values indicate significance at α<0.05 after False Discovery Rate (FDR) correction.  IgAN, IgA nephropathy; IgAV, IgA vasculitis; MCD, minimal change disease; MN, membranous nephropathy; FSGS, focal segmental glomerulosclerosis; uPCR, urine protein-to-creatinine ratio (g/g); eGFR, estimated glomerular filtration rate | | | | | | | | | | | | | |