

**Health Economic Impact of Nephrotic Syndrome in the United States Supplemental  
Material**

**Supplemental Table 1: Adult Survey Summary**

<b>Topic</b>	<b>Content Summary</b>
Initial and Follow-up tests	How and when diagnosis testing occurred, cost of testing
Medications, Vitamins, or Supplements	Type, dosage, and cost of various medications, vitamins, and supplements
Dialysis	Time and cost of dialysis
Kidney Transplant	Time and cost of kidney transplant
Plasmapheresis, Lipopheresis, & Other Therapies	Time and cost of various therapies
Diet	Time spent shopping for diet, description, cost, and difficult of following diet, professionals that monitor diet
Emergency Room Visits	Time and cost of ER visits
Hospitalizations	Time and cost of hospitalizations
Nephrology Visits	Time and cost of nephrology visits, blood drawn frequency
Primary Care Visits	Time and cost of primary care visits
Medical Specialist Visits	Time, cost, and frequency of seeing other specialists because of kidney disease
Special Services	Time, cost, and frequency of receiving special services for kidney disease
Insurance and Reimbursement	Type of insurance, time spent talking with insurance, reimbursements
Special Devices and Other Products	Types of products bought and cost of them
Modifications or Renovations	Types of modifications to homes and cost of them

Pregnancy	Impact of kidney disease on pregnancy, time to travel to nephrology practice during pregnancy, cost of visits
Childcare	Difficult and cost of finding childcare due to kidney disease
Work/School	Impact of kidney disease on work/school hours, costs for extra tutoring, missed work/school days
Demographics	Adult demographics

**Supplemental Table 2: Caregiver Survey Summary**

<b>Topic</b>	<b>Content Summary</b>
Initial and Follow-up tests	How and when diagnosis testing occurred, cost of testing for the child
Medications, Vitamins, or Supplements	Type, dosage, and cost of various medications, vitamins, and supplements for the child
Dialysis	Time and cost of dialysis for the child
Kidney Transplant	Time and cost of kidney transplant for the child
Plasmapheresis, Lipopheresis, & Other Therapies	Time and cost of various therapies for the child
Diet	Time spent shopping for diet, description, cost, and difficult of following diet, professionals that monitor the child's diet
Emergency Room Visits	Time and cost of the child's ER visits
Hospitalizations	Time and cost of the child's hospitalizations
Nephrology Visits	Time and cost of the child's nephrology visits, blood drawn frequency
Primary Care Visits	Time and cost of the child's primary care visits
Medical Specialist Visits	Time, cost, and frequency of the child seeing other specialists because of kidney disease
Special Services	Time, cost, and frequency for the child receiving special services for kidney disease
Insurance and Reimbursement	Type of insurance, time spent talking with insurance, reimbursements
Special Devices and Other Products	Types of products bought for the child and cost of them
Modifications or Renovations	Types of modifications to homes for the child and cost of them

Your Child With Kidney Disease	Impact of kidney disease on school hours and extra accommodations/ services, cost of childcare
Childcare for Your Other Childcare	Difficult and cost of finding childcare for the parent's other children who don't have kidney disease
How Having a Child with Kidney Disease Affects Parents'/Caregivers' Lives	Impact of child's kidney disease on parent's work/school hours
Child Demographics	Child demographics
Parent/Caregiver Demographics	Parent/Caregiver Demographics

**Supplemental Table 3: Selected Free Text Responses by Cost Domain**

	<b>Adult</b>	<b>Family Caregiver</b>
<b>Topic</b>	<b>Comment</b>	<b>Comment</b>
<b>Insurance Coverage</b>	I ... have chosen State Government as a profession which had tremendous health benefits. [City 1]	We were able to get [Private insurance] at that time and have things covered @ 100% [City 2]
	When hospitalized I had insurance through my employer. However, once I was unable to return to work my insurance was terminated (2 months later) and I went onto [State] medicaid program. Once on medicaid I had no expenses & it was paid 100%. [City 3]	I think we paid several hundred dollars for an ambulance ride from [City 3] to Children's hospital in [City 4] ... the rest of the charges were eventually paid by insurance and/or written off by [Community] Hospital in [City 3] after more than a year of communication with insurance co. and [Community Hospital] *everything at [Children's Hospital] was covered b/c it was in-network for our insurance. [City 4]
	Qualified for children special healthcare so have to only pay \$120 a year for health care related to my disease. [City 5]	
<b>Diet Difficulty</b>	Trying to find low sodium foods that I like. [City 6]	Due to COVID-19 my options are sometimes limited due to decreased income [City 7]
	I'm unemployed due to the disease and the sole income earner. Food banks do not cater to special diets. [City 8]	The foods are not difficult to get, but it is difficult to cook at home every day [City 4]
	specific products aren't difficult to get but in my areas where I've lived in the past year...there aren't many options except to cook for myself [City 9]	Sodium is so engrained into how we eat. It takes both time and money to adopt a fresher healthier lifestyle while eliminating so many products. [City 10]

	Vegan products are much more expensive and much more difficult to find. It's also hard to get the full complex of proteins.. I had to change my grocery store ...to find products that I need. It is more expensive than what I used to buy. [City 11]	He's a small child who can't have any of the foods normal kids his age eat. I've had to change the diet of our whole family so he doesn't feel singled out. Due to finances we aren't able to always buy the things he does like. [City 6]
	Temptation of old habits and favorite old foods always there [City 1]	My daughter has to take her "cold lunch to school while peers eat school prepared hot lunches." It is still easiest if I prepare her lunches and restrict outside after school activities by picking her up on time so she doesn't eat a lot or any salty, greasy foods... [City 12]
<b>Special accommodations at school/work</b>	off on disabled due to kidneys. Amputation of toes due to heart attack caused by kidney disease [City 13]	allowed to keep water on desk, extra bathroom breaks if needed [City 14]
		504 to accommodate absences [City 15]
<b>Other burdens</b>	I had a stroke 9 months ago- kidney related? due to long term prednisone use? I also had a bone density scan due to prednisone [City 13]	He is now 16, diagnosed at 11 he weighed 100 lbs then. He now weighs 265 at 5'8". I worry about his long term health and this weight and that he can't stay in remission. There have been many ER visits over the years when he's relapsed. Probably totaling \$4,000. [City 2]

**Supplemental Table 4. Adult: Non-ESKD vs ESKD Direct Out-of-Pocket Costs (USD)<sup>a</sup>**

	Non-ESKD (n=21)		ESKD (n=7)	
	# reporting, n (%)	Costs (USD) Median (IQR)	# reporting, N (%)	Costs (USD) Median (IQR)
<b>Medication</b>	18 (85.7)	191 (86-502)	7 (100)	264 (79-379)
<b>Diet</b>	13 (61.9)	1080 (600-2400)	3 (42.9)	1800 (1200-2100)
<b>Special Products<sup>b</sup></b>	11 (52.4)	60 (26-135)	5 (71.4)	0 (0-40)
<b>Emergency Room</b>	2 (9.5)	330 (265-395)	1 (14.3)	705 (705-705)
<b>Hospitalization</b>	4 (19)	918 (329-1435)	2 (28.6)	5073 (2584-7561)
<b>Nephrology Visit</b>	19 (90.5)	80 (54-135)	7 (100)	30 (15-233)
<b>Primary Care Provider Visit</b>	15 (71.4)	40 (23-72)	4 (57.1)	38 (15-69)
<b>Specialist Visit<sup>c</sup></b>	6 (28.6)	96 (48-154)	3 (42.9)	240 (145-1445)
<b>Other Services<sup>d</sup></b>	5 (23.8)	70 (37-80)	3 (42.9)	370 (235-390)
<b>Total</b>	21 (100)	2594 (728-4881)	7 (100)	3960 (3464-7109)

<sup>a</sup> United States Dollar

<sup>b</sup> Special products include blood pressure monitors, urine dipsticks, and other cleaning products.

<sup>c</sup> Specialists include Geneticists, Cardiologists, Dermatologists, Pulmonologists, and Optometrists

<sup>d</sup> Special Services include nutrition counseling, genetic counseling, behavioral therapy, social work, and the dentist

**Supplemental Table 5. Adult: Non-ESKD vs ESKD Indirect Costs (USD)**

	Non-ESKD (n=21)			ESKD (n=7)		
	# reporting, n (%)	Time Reported Median (IQR)	Time Costs (\$) Median (IQR) <sup>a</sup>	# reporting, n (%)	Time Reported Median (IQR)	Time Costs (\$) Median (IQR) <sup>a</sup>
<b>Emergency Room (hr)</b>	4 (19)	5.2 (3.6-8)	156 (108-240)	2 (28.6)	4 (2-6.4)	120 (60-192)
<b>Hospitalization (days)</b>	5 (23.8)	2 (2-4)	480 (480-960)	2 (28.6)	31 (26-36)	930 (780-1080)
<b>Nephrology Visit (hr)</b>	19 (90.5)	2.5 (1.5-4)	75 (45-120)	7 (100)	2.5 (1.5-4.5)	75 (45-135)
<b>Primary Care Provider Visit (hr)</b>	18 (85.7)	1.1 (1-1.9)	33 (30-57)	4 (57.1)	1.6 (1.3-1.8)	48 (39-54)
<b>Specialists Visit (hr)<sup>b</sup></b>	7 (33.3)	4.5 (2.3-6.4)	135 (69-192)	4 (57.1)	4.8 (2.5-8)	144 (75-240)
<b>Other Services Visit (hr)<sup>c</sup></b>	5 (23.8)	23.2 (18-36)	696 (540-1080)	2 (28.6)	10.5 (6.3-14.8)	315 (189-445)
<b>Traveling and shopping for special foods (hr)</b>	11 (52.4)	13 (1.5-48)	390 (45-1440)	3 (42.9)	24 (12-48)	720 (360-1440)
<b>Planning and prepping special meals (hr)</b>	11 (52.4)	182.5 (91.3-250.9)	5,477 (2740-7530)	2 (28.6)	228 (160-297)	6,842 (4802-8913)



<b>Speaking with insurance (hr)</b>	20 (95.2)	0 (0-1.6)	0 (0-48)	6 (85.7)	0 (0-0)	0 (0-0)
<b>Reduced work hours (hr)</b>	4 (19)	9 (6.8-12.5)	270 (204-375)	2 (28.6)	10 (5-15)	300 (150-450)
<b>Work absentee (days)</b>	21 (100)	1 (0-12)	30 (0-360)	7 (100)	0 (0-163)	0 (0-4892)
<b>School absentee(days)</b>	8 (38)	3 (0-8)	-	0 (0)	-	-
<b>Blood draws (#)</b>	21 (100)	10 (8-12)	300 (240-360)	7 (100)	12 (12-23)	360 (360-690)

<sup>a</sup> \$30.01 mean hourly earnings 2021 US\$

<sup>b</sup> Specialists include Geneticists, Cardiologists, Dermatologists, Pulmonologists, and Optometrists

<sup>c</sup> Other Services include nutrition counseling, genetic counseling, behavioral therapy, social work, and the dentist

**Supplemental Table 6. Caregiver: Non-ESKD vs ESKD Direct Costs (USD) <sup>a</sup>**

	Non-ESKD (n=15)		ESKD (n=2)	
	# reporting, n (%)	Costs (USD) Median (IQR)	# reporting, n (%)	Costs (USD) Median (IQR)
<b>Medication</b>	14 (93.3)	200 (43.5-385)	2 (100)	30 (15-45)
<b>Diet</b>	11 (73.3)	600 (275-966)	1 (50)	1000 (1000-1000)
<b>Special Product <sup>b</sup></b>	11 (73.3)	26 (0-50)	2 (100)	30 (15-45)
<b>Emergency Room</b>	1 (6.7)	10 (10-10)	0 (0)	-
<b>Hospitalization</b>	4 (26.7)	150 (83-1325)	0 (0)	0 (0)
<b>Nephrology Visit</b>	14 (93.3)	84 (61-110)	2 (100)	45 (43-48)
<b>Primary Care Provider Visit</b>	14 (93.3)	40 (21-86)	1 (50)	25 (25-25)
<b>Specialist Visit <sup>c</sup></b>	5 (33.3)	140 (50-600)	1 (50)	35 (35-35)
<b>Other Services <sup>d</sup></b>	3 (20)	70 (50-1135)	0 (0)	-
<b>Total</b>	14 (93.3)	1217 (608- 4214)	2 (100)	4985 (4343-5628)

<sup>a</sup> United States Dollar

<sup>b</sup> Special products include blood pressure monitors, urine dipsticks, and other cleaning products.

<sup>c</sup> Specialists include Geneticists, Cardiologists, Dermatologists, Pulmonologists, and Optometrists

<sup>d</sup> Other Services include nutrition counseling, genetic counseling, behavioral therapy, social work, and the dentist

**Supplemental Table 7. Caregiver: Non-ESKD vs ESKD Indirect Costs**

	Non-ESKD (n=15)			ESKD (n=2)		
	# reporting, n (%)	Time reported Median (IQR)	Time Costs (\$) Median (IQR) <sup>a</sup>	# reporting, n (%)	Time reported Median (IQR)	Time Costs (\$) Median (IQR) <sup>a</sup>
<b>Emergency Room (hr)</b>	1 (6.7)	5 (5-5)	150 (150-150)	0	-	-
<b>Hospitalization (days)</b>	4 (26.7)	2.5 (1-4)	600 (240-960)	0	-	-
<b>Nephrology Visit (hr)</b>	14 (93.3)	3.6 (2-4.4)	108 (60-132)	2 (100)	2.8 (2.4-3.1)	84 (72-93)
<b>Primary Care Provider Visit (hr)</b>	15 (100)	1.5 (1-2.3)	45 (30-69)	1 (50)	1.5 (1.5-1.5)	45 (45-45)
<b>Specialists Visit (hr)<sup>b</sup></b>	6 (40)	4.5 (2.5-5.8)	135 (75-174)	1 (50)	1 (1-1)	30 (30-30)
<b>Other Services Visit (hr)<sup>c</sup></b>	3 (20)	3 (2.4-6.5)	90 (72-195)	0 (0)	-	-
<b>Traveling and shopping for special foods (hr)</b>	12 (80)	9 (0.3-45)	270 (9-1350)	1 (50)	12 (12-12)	360 (360-360)
<b>Planning and prepping special meals (hr)</b>	9 (60)	182.5 (60.8-212.9)	5477 (1825-6389)	1 (50)	152 (152-152)	4562 (4562-4562)
<b>Speaking with insurance (hr)</b>	15 (100)	0.5 (0-1.75)	15 (0-53)	2 (100)	0.25 (.13-.38)	8 (4-11)
<b>Reduced work hours (hr)</b>	2 (13.3)	10 (7.5-12.5)	300 (225-375)	0	-	-
<b>Work absentee (days)</b>	14 (93.3)	4.5 (0-9.5)	1080 (0-2281)	1 (50)	7 (7-7)	1681 (1681-1681)

<b>School absentee (days)</b>	0	-	-	0 (0)	-	-
<b>Blood draws (#)</b>	14 (93.3)	4 (3-6)	-	2 (100)	9 (7.5-10.5)	-

<sup>a</sup> \$30.01 mean hourly earnings 2021 US\$

<sup>b</sup> Specialists include Geneticists, Cardiologists, Dermatologists, Pulmonologists, and Optometrists

<sup>c</sup> Other Services include nutrition counseling, genetic counseling, behavioral therapy, social work, and the dentist

**Supplemental Table 8. Non-ESKD Adult: Direct Out-of-Pocket Costs (USD)<sup>a</sup> by Insurance Type**

	Private (n=15)		Self (n=1)		Public or Public+ (n=3)	
	# reporting, n (%)	Costs (USD) Median (IQR)	# reporting, n (%)	Costs (USD) Median (IQR)	# reporting, n (%)	Costs (USD) Median (Range)
<b>Medication</b>	13 (86.7)	496 (155-4287)		210	3 (100)	0 (0-398)
<b>Diet</b>	8 (53.3)	900 (450-1950)		3600	1 (33.3)	4800
<b>Special Products<sup>b</sup></b>	10 (66.7)	48 (29-225)		--	2 (66.7)	30 (0-60)
<b>Emergency Room</b>	3 (20.0)	250 (145-355)		200	--	--
<b>Hospitalization</b>	2 (13.3)	1410 (725-1460)		--	1 (33.3)	425
<b>Nephrology Visit</b>	13 (86.7)	130 (80-170)		95	3 (100)	55 (2-57)
<b>Primary Care Provider Visit</b>	12 (80.0)	60 (25-100)		40	2 (66.7)	32 (25-40)
<b>Specialist Visit<sup>c</sup></b>	4 (26.7)	360 (200-1430)		72	2 (66.7)	143 (120-165)
<b>Other Services<sup>d</sup></b>	3 (20.0)	98 (84-111)		--	1 (33.3)	80
<b>Total</b>	15 (100.0)	3155 (800-6676)		5227	3 (100)	670 (2-5595)

<sup>a</sup> United States Dollar

<sup>b</sup> Special products include blood pressure monitors, urine dipsticks, and other cleaning products.

<sup>c</sup> Specialists include Geneticists, Cardiologists, Dermatologists, Pulmonologists, and Optometrists

<sup>d</sup> Special Services include nutrition counseling, genetic counseling, behavioral therapy, social work, and the dentist

**Supplemental Table 9. Non-ESKD Caregiver: Direct Out-of-Pocket Costs (USD)<sup>a</sup> by Insurance Type**

	Private (n=7)		Public + CSH (n=3)	
	# reporting, n (%)	Costs (USD) Median (IQR)	# reporting, n (%)	Costs (USD) Median (range)
<b>Medication</b>	7 (100)	210 (75-528)	3 (100)	0 (0-54)
<b>Diet</b>	4 (57.1)	750 (463-900)	3 (100)	1032 (0-3600)
<b>Special Products<sup>b</sup></b>	4 (57.1)	0 (0.12.5)	3 (100)	26.42 (0-30)
<b>Emergency Room</b>	1 (14.2)	10	--	--
<b>Hospitalization</b>	2 (28.4)	115 (73-158)	1 (33.3)	100
<b>Nephrology Visit</b>	6 (85.7)	105 (66-110)	3 (100)	65 (15-90)
<b>Primary Care Provider Visit</b>	6 (85.7)	31 (21-81)	3 (100)	40 (0-195)
<b>Specialist Visit<sup>c</sup></b>	1 (14.2)	140	1 (100)	50
<b>Other Services<sup>d</sup></b>	1 (14.2)	220	1 (33.3)	30
<b>Total</b>	7 (100)	859 (481-1309)	3 (100)	1322 (350-3875)

<sup>a</sup> United States Dollar

<sup>b</sup> Special products include blood pressure monitors, urine dipsticks, and other cleaning products.

<sup>c</sup> Specialists include Geneticists, Cardiologists, Dermatologists, Pulmonologists, and Optometrists

<sup>d</sup> Special Services include nutrition counseling, genetic counseling, behavioral therapy, social work, and the dentist