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DATASET: F37-43

Focal Segmental Glomerulosclerosis (FSGS) Clinical Trial
Pediatric Quality of Life Inventory (PedsQL) Version 4.0
Parent Report for Toddlers (ages 2-4) (Form # 37)

1. Participant ID Number PID	2.Alpha Code ALPHCD	3.Visit Number VISN SUBN	4. Date Questionnaire Administered (dd/mmm/yyyy) VISDT

For Data Entry Purposes Only: Verify the form number that you are trying to enter..... PQOLN

5. Does the participant speak a language that this form is available in? ..... (0 = no, 1 = yes) P_LANG

6. What version was used?..... (1 = English, 2 = Spanish, 3 = French) LANG

7. How was the questionnaire administered? .. (1 = Self-administered, 2 = Interview-administered) QADMIN

8. If this form was interview-administered (Q7=2), for what primary reason was this done?. INTVWR
   1 = visual
   2 = dexterity
   3 = literacy
   4 = comprehension
   5 = participant/parent preference
   6 = Study Coordinator preference
   8 = not applicable

9. Setting where this form was completed?..... SETTIN
   1 = completed in a clinical setting
   2 = completed at participant's home by the participant
   3 = completed at participant's home by a family member

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--
10. Are you ready to key enter this form?.....(0 = no, 1 = yes) __READY

--

PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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In the past **ONE month,** how much of a **problem** has your child had with …

PHYSICAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
11. Walking PQOL PF1	0	1	2	3	4
12. Running PQOL PF2	0	1	2	3	4
13. Participating in active play or exercise PQOLPF3	0	1	2	3	4
14. Lifting something heavy PQOLPF4	0	1	2	3	4
15. Bathing PQOLPF5	0	1	2	3	4
16. Helping to pick up his or her toys PQOLPF6	0	1	2	3	4
17. Having hurts or aches PQOLPF7	0	1	2	3	4
18. Low energy level PQOLPF8	0	1	2	3	4

EMOTIONAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
19. Feeling afraid or scared PQOLEM1	0	1	2	3	4
20. Feeling sad or blue PQOLEM2	0	1	2	3	4
21. Feeling angry PQOLEM3	0	1	2	3	4
22. Trouble sleeping PQOLEM4	0	1	2	3	4
23. Worrying PQOLEM5	0	1	2	3	4

SOCIAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
24. Playing with other children PQOLSF1	0	1	2	3	4
25. Other kids not wanting to play with him or her PQOLSF2	0	1	2	3	4
26. Getting teased by other children PQOLSF3	0	1	2	3	4
27. Not able to do things that other children his or her age can do PQOLSF4	0	1	2	3	4
28. Keeping up when playing with other children PQOLSF5	0	1	2	3	4

Please complete this section if your child attends school or daycare

SCHOOL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
29. Doing the same school activities as peers PQOLSC3	0	1	2	3	4
30. Missing school/daycare because of not feeling well	0	1	2	3	4 PQOLSC4
31. Missing school/daycare to go to the doctor or hospital PQOLSC5	0	1	2	3	4

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200. Date this form reviewed.....(dd/mmm/yyyy) ___ ___/___ ___ ___/___ ___ ___ ___ COMPDT

201. Username of person reviewing this form.....___ ___ ___ ___ ___ ___ ___ ___ COMPBY

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DATASET: F37

Focal Segmental Glomerulosclerosis (FSGS) Clinical Trial
Pediatric Quality of Life Inventory (PedsQL) Version 4.0
Young Child Report (ages 5-7) (Form # 38)

1. Participant ID Number	2. Alpha Code	3. Visit Number	4. Date Questionnaire Administered (dd/mmm/yyyy)
P ID	ALPHCD	VISN SUBN	VISDT

For Data Entry Purposes Only: Verify the form number that you are trying to enter..... PQOLN

5. Does the participant speak a language that this form is available in?.....(0 = no, 1 = yes) P_LANG

6. What version was used?..... (1 = English, 2 = Spanish, 3 = French) LANG

7. How was the questionnaire administered? ...(1 = Self-administered, 2 = Interview-administered) QADMIN

8. If this form was interview-administered (Q7=2), for what primary reason was this done?. INTVWR
   1 = visual
   2 = dexterity
   3 = literacy
   4 = comprehension
   5 = participant/parent preference
   6 = Study Coordinator preference
   8 = not applicable

9. Setting where this form was completed?..... SETTIN
   1 = completed in a clinical setting
   2 = completed at participant's home by the participant
   3 = completed at participant's home by a family member

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10. Are you ready to key enter this form?.....(0 = no, 1 = yes) __READY

Young Child Report (ages 5-7)

Instructions for interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.

Show the child the template and point to the responses as you read.

If it is not at all a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is a problem for you a lot, point to the frowning face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

	Not at all	Sometimes	A lot
Is it hard for you to snap your fingers	☺	😐	☹

Ask the child to demonstrate snapping his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

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Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

PHYSICAL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot	
11. Is it hard for you to walk	0	2	4	PQOLPF1
12. Is it hard for you to run	0	2	4	PQOLPF2
13. Is it hard for you to play sports or exercise	0	2	4	PQOLPF3
14. Is it hard for you to pick up big things	0	2	4	PQOLPF4
15. Is it hard for you to take a bath or shower	0	2	4	PQOLPF5
16. Is it hard for you to do chores (like pick up your toys)	0	2	4	PQOLPF6
17. Do you have hurts or aches (*Where?*_____)	0	2	4	PQOLPF7
18. Do you ever feel too tired to play	0	2	4	PQOLPF8

Remember, tell me how much of a problem this has been for you for the last few weeks.

EMOTIONAL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot	
19. Do you feel scared	0	2	4	PQOLEM1
20. Do you feel sad	0	2	4	PQOLEM2
21. Do you feel mad	0	2	4	PQOLEM3
22. Do you have trouble sleeping	0	2	4	PQOLEM4
23. Do you worry about what will happen to you	0	2	4	PQOLEM5

SOCIAL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot	
24. Is it hard for you to get along with other kids	0	2	4	PQOLSF1
25. Do other kids say they do not want to play with you	0	2	4	PQOLSF2
26. Do other kids tease you	0	2	4	PQOLSF3
27. Can other kids do things that you cannot do	0	2	4	PQOLSF4
28. Is it hard for you to keep up when you play with other kids	0	2	4	PQOLSF5

SCHOOL FUNCTIONING *(problems with...)*	Not at all	Some-times	A lot	
29. Is it hard for you to pay attention in school	0	2	4	PQOLSC1
30. Do you forget things	0	2	4	PQOLSC2
31. Is it hard to keep up with schoolwork	0	2	4	PQOLSC3
32. Do you miss school because of not feeling good	0	2	4	PQOLSC4
33. Do you miss school because you have to go to the doctor's or hospital	0	2	4	PQOLSC5

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201. Username of person reviewing this form ..... ___ ___ ___ ___ ___ ___ ___ ___ COMPBY

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203. Username of person entering this form ("By")

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How much of a problem is this for you?

Not at all

Sometimes

A lot

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DATASET : F37

Focal Segmental Glomerulosclerosis (FSGS) Clinical Trial
Pediatric Quality of Life Inventory (PedsQL) Version 4.0
Parent Report for Young Children (ages 5-7) (Form # 39)

1. Participant ID Number	2.Alpha Code	3.Visit Number	4. Date Questionnaire Administered (dd/mmm/yyyy)
PID	ALPHCD	VISN SUBN	VISDT

For Data Entry Purposes Only: Verify the form number that you are trying to enter..... __P__ POOL N

5. Does the participant speak a language that this form is available in? ..... (0 = no, 1 = yes) __P__ -LANG

6. What version was used?..... (1 = English, 2 = Spanish, 3 = French) __LANG

7. How was the questionnaire administered? .. (1 = Self-administered, 2 = Interview-administered) __Q__ ADMIN

8. If this form was interview-administered (Q7=2), for what primary reason was this done?. __INTVWR
   1 = visual
   2 = dexterity
   3 = literacy
   4 = comprehension
   5 = participant/parent preference
   6 = Study Coordinator preference
   8 = not applicable

9. Setting where this form was completed?..... __S__ ETTIN
   1 = completed in a clinical setting
   2 = completed at participant's home by the participant
   3 = completed at participant's home by a family member

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10. Are you ready to key enter this form?.....(0 = no, 1 = yes) ___READY

Parent Report for Young Children (ages 5-7)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child.** Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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*In the past **ONE month,** how much of a **problem** has your child had with …*

PHYSICAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always	
11. Walking more than one block	0	1	2	3	4	PQOLPF1
12. Running	0	1	2	3	4	PQOLPF2
13. Participating in sports activity or exercise	0	1	2	3	4	PQOLPF3
14. Lifting something heavy	0	1	2	3	4	PQOLPF4
15. Taking a bath or shower by him or herself	0	1	2	3	4	PQOLPF5
16. Doing chores, like picking up his or her toys	0	1	2	3	4	PQOLPF6
17. Having hurts or aches	0	1	2	3	4	PQOLPF7
18. Low energy level	0	1	2	3	4	PQOL PF8

EMOTIONAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always	
19. Feeling afraid or scared	0	1	2	3	4	PQOLEM1
20. Feeling sad or blue	0	1	2	3	4	PQOLEM2
21. Feeling angry	0	1	2	3	4	PQOLEM3
22. Trouble sleeping	0	1	2	3	4	PQOLEM4
23. Worrying about what will happen to him or her	0	1	2	3	4	PQOLEM5

SOCIAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always	
24. Getting along with other children	0	1	2	3	4	PQOLSF1
25. Other kids not wanting to be his or her friend	0	1	2	3	4	PQOLSF2
26. Getting teased by other children	0	1	2	3	4	PQOLSF3
27. Not able to do things that other children his or her age can do	0	1	2	3	4	PQOLSF4
28. Keeping up when playing with other children	0	1	2	3	4	PQOLSF5

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SCHOOL FUNCTIONING *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
29. Paying attention in class	0	1	2	3	4	PQOLSC1
30. Forgetting things	0	1	2	3	4	PQOLSC2
31. Keeping up with school activities	0	1	2	3	4	PQOLSC3
32. Missing school because of not feeling well	0	1	2	3	4	PQOLSC4
33. Missing school to go to the doctor or hospital	0	1	2	3	4	PQOLSC5

200. Date this form reviewed.....(dd/mmm/yyyy) ___ ___/___ ___ ___/___ ___ ___ ___ COMPDT

201. Username of person reviewing this form..... ___ ___ ___ ___ ___ ___ ___ COMPBY

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203. Username of person entering this form ("By")

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DATASET: F37

Focal Segmental Glomerulosclerosis (FSGS) Clinical Trial
Pediatric Quality of Life Inventory (PedsQL) Version 4.0
Child Report (ages 8-12) (Form # 40)

1. Participant ID Number	2.Alpha Code	3.Visit Number	4. Date Questionnaire Administered (dd/mmm/yyyy)
PID	ALPHCD	VISN SUBN	VISDT

For Data Entry Purposes Only: Verify the form number that you are trying to enter..... PQOLN

5. Does the participant speak a language that this form is available in? ..... (0 = no, 1 = yes) P-LANG

6. What version was used?..... (1 = English, 2 = Spanish, 3 = French) LANG

7. How was the questionnaire administered? .. (1 = Self-administered, 2 = Interview-administered) QADMIN

8. If this form was interview-administered (Q7=2), for what primary reason was this done?. INTVWR
   1 = visual
   2 = dexterity
   3 = literacy
   4 = comprehension
   5 = participant/parent preference
   6 = Study Coordinator preference
   8 = not applicable

9. Setting where this form was completed?..... SETTN
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   2 = completed at participant's home by the participant
   3 = completed at participant's home by a family member

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10. Are you ready to key enter this form?.....(0 = no, 1 = yes) READY

Child Report (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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*In the past **ONE month**, how much of a **problem** has this been for you ...*

ABOUT MY HEALTH AND ACTIVITIES *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
11. It is hard for me to walk more than one block	0	1	2	3	4	PQOLPF1
12. It is hard for me to run	0	1	2	3	4	PQOLPF2
13. It is hard for me to do sports activity or exercise	0	1	2	3	4	PQOLPF3
14. It is hard for me to lift something heavy	0	1	2	3	4	PQOLPF4
15. It is hard for me to take a bath or shower by myself	0	1	2	3	4	PQOLPF5
16. It is hard for me to do chores around the house	0	1	2	3	4	PQOLPF6
17. I hurt or ache	0	1	2	3	4	PQOLPF7
18. I have low energy	0	1	2	3	4	PQOLPF8

ABOUT MY FEELINGS *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
19. I feel afraid or scared	0	1	2	3	4	PQOLEM1
20. I feel sad or blue	0	1	2	3	4	PQOLEM2
21. I feel angry	0	1	2	3	4	PQOLEM3
22. I have trouble sleeping	0	1	2	3	4	PQOLEM4
23. I worry about what will happen to me	0	1	2	3	4	PQOLEM5

HOW I GET ALONG WITH OTHERS *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
24. I have trouble getting along with other kids	0	1	2	3	4	PQOLSF1
25. Other kids do not want to be my friend	0	1	2	3	4	PQOLSF2
26. Other kids tease me	0	1	2	3	4	PQOLSF3
27. I cannot do things that other kids my age can do	0	1	2	3	4	PQOLSF4
28. It is hard to keep up when I play with other kids	0	1	2	3	4	PQOLSF5

ABOUT SCHOOL *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
29. It is hard to pay attention in class	0	1	2	3	4	PQOLSC1
30. I forget things	0	1	2	3	4	PQOLSC2
31. I have trouble keeping up with my schoolwork	0	1	2	3	4	PQOLSC3
32. I miss school because of not feeling well	0	1	2	3	4	PQOLSC4
33. I miss school to go to the doctor or hospital	0	1	2	3	4	PQOLSC5

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201. Username of person reviewing this form.....___ ___ ___ ___ ___ ___ COMPBY

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203. Username of person entering this form ("By")

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DATASET: F37

Focal Segmental Glomerulosclerosis (FSGS) Clinical Trial Pediatric Quality of Life Inventory (PedsQL) Version 4.0 Parent Report for Children (ages 8-12) (Form # 41)

1. Participant ID Number	2. Alpha Code	3. Visit Number	4. Date Questionnaire Administered (dd/mmm/yyyy)
PID	ALPHCD	VISN SUBN	VISDT

For Data Entry Purposes Only: Verify the form number that you are trying to enter..... __P__ PQOLN

5. Does the participant speak a language that this form is available in? ..... (0 = no, 1 = yes) __P__ P_LANG

6. What version was used?..... (1 = English, 2 = Spanish, 3 = French) __L__ LANG

7. How was the questionnaire administered? .. (1 = Self-administered, 2 = Interview-administered) __Q__ QADMIN

8. If this form was interview-administered (Q7=2), for what primary reason was this done?. __I__ INTVWR
   1 = visual
   2 = dexterity
   3 = literacy
   4 = comprehension
   5 = participant/parent preference
   6 = Study Coordinator preference
   8 = not applicable

9. Setting where this form was completed?..... __S__ SETTIN
   1 = completed in a clinical setting
   2 = completed at participant's home by the participant
   3 = completed at participant's home by a family member

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10. Are you ready to key enter this form?.....(0 = no, 1 = yes) __READY

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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*In the past **ONE month,** how much of a **problem** has your child had with ...*

PHYSICAL FUNCTIONING *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
11. Walking more than one block	0	1	2	3	4	PQOL PF1
12. Running	0	1	2	3	4	PQOL PF2
13. Participating in sports activity or exercise	0	1	2	3	4	PQOL PF3
14. Lifting something heavy	0	1	2	3	4	PQOL PF4
15. Taking a bath or shower by him or herself	0	1	2	3	4	PQOL PF5
16. Doing chores around the house	0	1	2	3	4	PQOL PF6
17. Having hurts or aches	0	1	2	3	4	PQOL PF7
18. Low energy level	0	1	2	3	4	PQOL PF8

EMOTIONAL FUNCTIONING *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
19. Feeling afraid or scared	0	1	2	3	4	PQOL EM1
20. Feeling sad or blue	0	1	2	3	4	PQOL EM2
21. Feeling angry	0	1	2	3	4	PQOL EM3
22. Trouble sleeping	0	1	2	3	4	PQOL EM4
23. Worrying about what will happen to him or her	0	1	2	3	4	PQOL EM5

SOCIAL FUNCTIONING *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
24. Getting along with other children	0	1	2	3	4	PQOL SF1
25. Other kids not wanting to be his or her friend	0	1	2	3	4	PQOL SF2
26. Getting teased by other children	0	1	2	3	4	PQOL SF3
27. Not able to do things that other children his or her age can do	0	1	2	3	4	PQOL SF4
28. Keeping up when playing with other children	0	1	2	3	4	PQOL SF5

SCHOOL FUNCTIONING *(problems with...)*	Never	Almost Never	Some-times	Often	Almost Always	
29. Paying attention in class	0	1	2	3	4	PQOL SC1
30. Forgetting things	0	1	2	3	4	PQOL SC2
31. Keeping up with schoolwork	0	1	2	3	4	PQOL SC3
32. Missing school because of not feeling well	0	1	2	3	4	PQOL SC4
33. Missing school to go to the doctor or hospital	0	1	2	3	4	PQOL SC5

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202. Date this form entered (dd/mmm/yyyy) ("Created On")

203. Username of person entering this form ("By")

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DATASET: F37

Focal Segmental Glomerulosclerosis (FSGS) Clinical Trial
Pediatric Quality of Life Inventory (PedsQL) Version 4.0
Teen Report (ages 13-18) (Form # 42)

1. Participant ID Number	2. Alpha Code	3. Visit Number	4. Date Questionnaire Administered (dd/mmm/yyyy)
PID	ALPHCD	VISN SUBN	VISDT

For Data Entry Purposes Only: Verify the form number that you are trying to enter..... QOLN

5. Does the participant speak a language that this form is available in? ..... (0 = no, 1 = yes) P-LANG

6. What version was used?..... (1 = English, 2 = Spanish, 3 = French) LANG

7. How was the questionnaire administered? .. (1 = Self-administered, 2 = Interview-administered) QADMIN

8. If this form was interview-administered (Q7=2), for what primary reason was this done?. INTVWR
   1 = visual
   2 = dexterity
   3 = literacy
   4 = comprehension
   5 = participant/parent preference
   6 = Study Coordinator preference
   8 = not applicable

9. Setting where this form was completed?..... SITTIN
   1 = completed in a clinical setting
   2 = completed at participant's home by the participant
   3 = completed at participant's home by a family member

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10. Are you ready to key enter this form?.....(0 = no, 1 = yes) READY

TEEN REPORT (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

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*In the past **ONE month**, how much of a **problem** has this been for you ...*

ABOUT MY HEALTH AND ACTIVITIES *(problems with...)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
11. It is hard for me to walk more than one block	0	1	2	3	4	PQOLPF1
12. It is hard for me to run	0	1	2	3	4	PQOLPF2
13. It is hard for me to do sports activity or exercise	0	1	2	3	4	PQOLPF3
14. It is hard for me to lift something heavy	0	1	2	3	4	PQOLPF4
15. It is hard for me to take a bath or shower by myself	0	1	2	3	4	PQOLPF5
16. It is hard for me to do chores around the house	0	1	2	3	4	PQOL PF6
17. I hurt or ache	0	1	2	3	4	PQOL PF7
18. I have low energy	0	1	2	3	4	PQOL PF8

ABOUT MY FEELINGS *(problems with...)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
19. I feel afraid or scared	0	1	2	3	4	PQOLEM1
20. I feel sad or blue	0	1	2	3	4	PQOLEM2
21. I feel angry	0	1	2	3	4	PQOLEM3
22. I have trouble sleeping	0	1	2	3	4	PQOL EMY
23. I worry about what will happen to me	0	1	2	3	4	PQOL EMS

HOW I GET ALONG WITH OTHERS *(problems with...)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
24. I have trouble getting along with other teens	0	1	2	3	4	PQOLSF1
25. Other teens do not want to be my friend	0	1	2	3	4	PQOL SF2
26. Other teens tease me	0	1	2	3	4	PQOLSF3
27. I cannot do things that other teens my age can do	0	1	2	3	4	PQOLSF4
28. It is hard to keep up with my peers	0	1	2	3	4	PQOLSF5

ABOUT SCHOOL *(problems with...)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
29. It is hard to pay attention in class	0	1	2	3	4	PQOLSC1
30. I forget things	0	1	2	3	4	PQOLSC2
31. I have trouble keeping up with my schoolwork	0	1	2	3	4	PQOLSC3
32. I miss school because of not feeling well	0	1	2	3	4	PQOL SC4
33. I miss school to go to the doctor or hospital	0	1	2	3	4	PQOL SC5

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200. Date this form reviewed.....(dd/mmm/yyyy) ___ ___/___ ___ ___/___ ___ ___ ___ COMPDT

201. Username of person reviewing this form.....___ ___ ___ ___ ___ ___ ___ COMPBY

Automatically stored:

202. Date this form entered (dd/mmm/yyyy) ("Created On")

203. Username of person entering this form ("By")

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DATASET: F37

Focal Segmental Glomerulosclerosis (FSGS) Clinical Trial Pediatric Quality of Life Inventory (PedsQL) Version 4.0 Parent Report for Teens (ages 13-18) (Form # 43)

1. Participant ID Number	2. Alpha Code	3. Visit Number	4. Date Questionnaire Administered (dd/mmm/yyyy)
PID	ALPHCD	VISN SUBN	VISDT

For Data Entry Purposes Only: Verify the form number that you are trying to enter..... QOLN

5. Does the participant speak a language that this form is available in? ..... (0 = no, 1 = yes) P-LANG

6. What version was used?..... (1 = English, 2 = Spanish, 3 = French) LANG

7. How was the questionnaire administered? .. (1 = Self-administered, 2 = Interview-administered) QADMIN

8. If this form was interview-administered (Q7=2), for what primary reason was this done?. INTVWR
   1 = visual
   2 = dexterity
   3 = literacy
   4 = comprehension
   5 = participant/parent preference
   6 = Study Coordinator preference
   8 = not applicable

9. Setting where this form was completed?..... SETTIN
   1 = completed in a clinical setting
   2 = completed at participant's home by the participant
   3 = completed at participant's home by a family member

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10. Are you ready to key enter this form?.....(0 = no, 1 = yes) READY

PARENT REPORT for TEENS (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for **your teen**. Please tell us **how much of a problem** each one has been for **your teen** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
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In the past **ONE month,** how much of a **problem** has your teen had with …

PHYSICAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
11. Walking more than one block	0	1	2	3	4	PQOL PF1
12. Running	0	1	2	3	4	PQOL PF2
13. Participating in sports activity or exercise	0	1	2	3	4	PQOL PF3
14. Lifting something heavy	0	1	2	3	4	PQOL PF4
15. Taking a bath or shower by him or herself	0	1	2	3	4	PQOL PF5
16. Doing chores around the house	0	1	2	3	4	PQOL PF6
17. Having hurts or aches	0	1	2	3	4	PQOL PF7
18. Low energy level	0	1	2	3	4	PQOL PF8

EMOTIONAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
19. Feeling afraid or scared	0	1	2	3	4	PQOL EM1
20. Feeling sad or blue	0	1	2	3	4	PQOL EM2
21. Feeling angry	0	1	2	3	4	PQOL EM3
22. Trouble sleeping	0	1	2	3	4	PQOL EM4
23. Worrying about what will happen to him or her	0	1	2	3	4	PQOL EM5

SOCIAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
24. Getting along with other teens	0	1	2	3	4	PQOL SF1
25. Other teens not wanting to be his or her friend	0	1	2	3	4	PQOL SF2
26. Getting teased by other teens	0	1	2	3	4	PQOL SF3
27. Not able to do things that other teens his or her age can do	0	1	2	3	4	PQOL SF4
28. Keeping up with other teens	0	1	2	3	4	PQOL SF5

SCHOOL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**	
29. Paying attention in class	0	1	2	3	4	PQOL SC1
30. Forgetting things	0	1	2	3	4	PQOL SC2
31. Keeping up with schoolwork	0	1	2	3	4	PQOL SC3
32. Missing school because of not feeling well	0	1	2	3	4	PQOL SC4
33. Missing school to go to the doctor or hospital	0	1	2	3	4	PQOL SC5

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