



Item S2: CureGN Parent Proxy Pediatric Quality of Life Questionnaire (Parents of Children 0-10yrs)

Please indicate on the picture where your child has had swelling in the past 7 days. Then, indicate how **severe** it was at each location **at its worst** in the **past 7 days**.

	Absent <span style="float: right;">Worst Imaginable</span>					
A. Swelling in your child's:						
1. Whole body	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Face or around your eyes	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Fingers or hands	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. Arms	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Stomach or abdomen	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Genitalia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. Legs	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. Feet	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Please indicate how severe each kidney disease symptom was in the past 7 days</b>	<b>Absent</b>	<b>Mild</b>				<b>Worst Imaginable</b>
B1. Pain where your child has swelling or pressure	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B2. Shortness of breath	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B3. Trouble falling asleep	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B4. Waking up at night	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<b>Please respond to each item by marking ONE box per row.</b>	<b>Excellent</b>	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	
C1. In general, would you say your child's health is:	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
C2. In general, would you say your child's quality of life is:	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
C3. In general, how would you rate your child's physical health?	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
C4. In general, how would you rate your child's mental health, including mood and ability to think?	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
	<b>Always</b>	<b>Often</b>	<b>Sometimes</b>	<b>Rarely</b>	<b>Never</b>	
C5. How often does your child feel really sad?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
C6. How often does your child have fun with friends or family?	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	
	<b>Not Applicable</b>	<b>Never</b>	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
C7. Being tired made it hard for my child to play or go out with friends or family.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C8. My child was weak.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C9. My child got tired easily.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C10. Being tired made it hard for my child to keep up with schoolwork.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C11. My child had trouble finishing things because of being too tired.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C12. My child had trouble starting things because of being too tired.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C13. My child was so tired it was hard for her/him to pay attention.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C14. My child was too tired to do sports or exercise.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C15. My child was too tired to do things outside.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C16. My child was too tired to enjoy the things s/he likes to do.	<input type="checkbox"/> 95	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

In the past 7 days.....	Not Applicable	With No Trouble	With a Little Trouble	With Some Trouble	With a Lot of Trouble	Not Able to Do
D1. My child could do physical activities that other same-age kids could do.	<input type="checkbox"/> 95	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
D2. My child could keep up when playing with other kids.	<input type="checkbox"/> 95	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
D3. My child could walk up stairs without holding onto anything.	<input type="checkbox"/> 95	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
D4. My child was physically able to do the activities s/he enjoys most.	<input type="checkbox"/> 95	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

### Medication Questions

For kidney disease medication to work, people have to take it according to their doctor’s instructions. For one reason or another, people can’t or don’t always take all of their pills as prescribed. We want to know how often your child has missed kidney disease medication. Please answer the following.

E1. Is your child supposed to be taking medications for his or her kidney disease?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
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If yes, over the past 7 days...	Strongly Disagree				Strongly Agree	Not Applicable
E2. My child took all doses of their kidney disease medication.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
E3. My child missed or skipped at least one dose of their kidney disease medication.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
E4. My child was not able to take all of their kidney disease medication.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95

Sometimes it is difficult for people to take their medications. In the **past 7 days**, how much did each of these specific situations contribute to your child missing a dose of kidney disease medication?

In the past 7 days...	Not at All				Very Much	Not Applicable
F1. I forgot.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
F2. I was busy.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
F3. My child was busy.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
F4. The medicine caused some side effects.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
F5. The medicine cost a lot of money.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
F6. I felt my child did not need the medicine.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
F7. We ran out of medication.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95
F8. My child was feeling too ill to take the medicine.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 95

Thank You