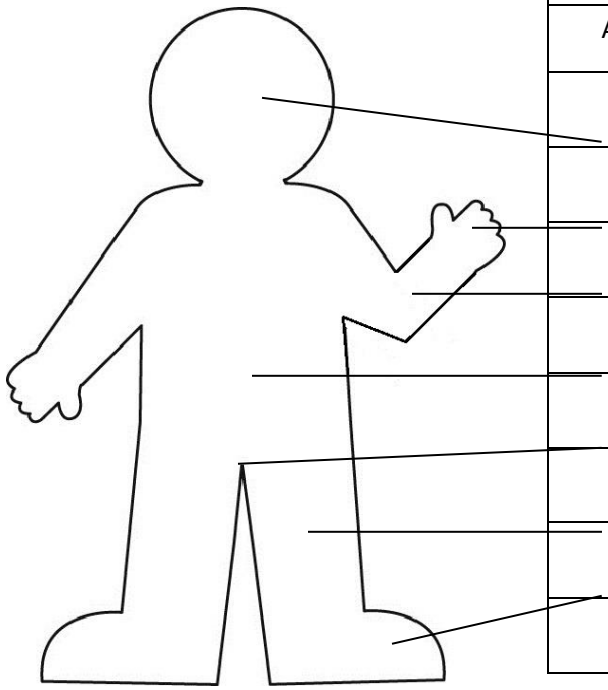
Item S3: CureGN Adult Quality of Life Questionnaire (Ages 18+)

Please indicate on the picture where you have 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					**Worst Imaginable**
A. Swelling in your:						
1. Whole body	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. Face or around your eyes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. Fingers or hands	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. Arms	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Stomach or abdomen	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Genitalia	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Legs	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Feet	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

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Please indicate how severe each kidney disease symptom was in the past 7 days	**Absent**	**Mild**				**Worst Imaginable**
B1. Pain where you have swelling or pressure	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B2. Shortness of breath	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B3. Trouble falling asleep	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
B4. Waking up at night	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Please respond to each item by Marking ONE box per row.	**Excellent**	**Very Good**	**Good**	**Fair**	**Poor**
C1. In general, would you say your health is:	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
C2. In general, would you say your quality of life is:	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
C3. In general, how would you rate your physical health?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
C4. In general, how would you rate your mental health, including your mood and your ability to think?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
C5. In general, how would you rate your satisfaction with your social activities and relationships?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
C6. In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
	Completely	**Mostly**	**Moderately**	**A Little**	**Not at All**
C7. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In the past 7 days…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
D1. How often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	None	**Mild**	**Moderate**	**Severe**	**Very Severe**
D2. How would you rate your fatigue on average?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	No Pain										**Worst Imaginable Pain**
D3. How would you rate your pain on average?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10

10/1/14

In the past 7 days...	Never	Rarely	Sometimes	Often	Always
D4. I felt worried.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D5. I felt stressed.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D6. How often did you feel tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D7. How often did you experience extreme exhaustion?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D8. How often did you run out of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D9. How often did your fatigue limit you at work (including work at home)?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D10. How often were you too tired to think clearly?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D11. How often were you too tired to take a bath or shower?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
D12. How often did you have enough energy to exercise strenuously?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
	Not at All	**A Little Bit**	**Somewhat**	**Quite a Bit**	**Very Much**
D13. I had problems during the day because of poor sleep.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

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 you have missed kidney disease medication. Please rate your agreement with the following statements.

	Yes	No
E1. Are you supposed to be taking medications for your kidney disease?	☐	☐

If yes, in the past 7 days...	Strongly Disagree				Strongly Agree	Not Applicable
E2. I took all doses of my kidney disease medication.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
E3. I missed or skipped at least one dose of my kidney disease medication.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
E4. I was not able to take all of my kidney disease medication.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95

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Sometimes it is difficult for people to take their medications. We would like to know if any of the following reasons are why you missed a dose of your kidney disease medication **in the past 7 days**.

In the past 7 days...	**Not at All**				**Very Much**	**Not Applicable**
F1. I forgot.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
F2. I was busy.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
F3. They caused some side effects.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
F4. They cost a lot of money.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
F5. I was afraid they may affect my sexual performance.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
F6. I felt I did not need them.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
F7. I ran out of medication.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95
F8. I was feeling too ill to take them.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 95

Thank You