Dialysis Patient Perspective Survey

Dear Patient,

Thank you for agreeing to take this survey and be a part of this important project. You will remain completely anonymous. If you do not want to take this survey, please give the packet back to the person who gave it to you so that someone else can participate.

BioTrends and the National Kidney Foundation (NKF) are conducting this survey to better understand the issues that you and other dialysis patients face. Our goal is to learn more about patients’ experience with kidney disease, the need for educational information about the disease and issues around treatment.

By completing this survey you are helping us to better design programs and services to meet the needs of dialysis patients.

Once you have completed the survey, please return it to your Renal Dietician or Social Worker who gave it to you so that they can submit to us. To thank you for your participation, you will be receiving a $25 American Express gift card once we receive your completed survey.

If you have any questions, please feel free to call BioTrends (610.363.3872) or Anthony Gucciardo, Vice President of Corporate Relations at the National Kidney Foundation (1.800.622.9010 x205).
Patient Background Section

Please tell us about yourself.

1. How old are you? ____________ years old

2. What is your marital status? Please check one
   - Single
   - Married
   - Divorced
   - Widowed

3. What is your gender?
   - Male
   - Female

4. What is your employment status? Please check one
   - I am working full time
   - I am working part-time
   - I am not working at this time
   - I am retired
   - Other

5. What are your hobbies / interests? Please describe

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

6. Which best describes how you interact with other people at your dialysis center? Please check one
   - I prefer to keep to myself
   - I prefer to socialize with a small group of other patients
   - I prefer to be very involved in my dialysis center with other patients and staff

7. What kind of insurance do you have to pay for the drugs you take by mouth? Please check one
   - Medicare Part D only
   - Drug coverage through my employer (Employer Group Health Plan)
   - Both Medicare Part D and drug coverage through my employer
   - I do not have insurance coverage for the drugs I take by mouth

8. About how much money do you bring home in a month?

   Monthly Amount: $______________
9. About how much of your money do you spend a month on your drugs, including those your doctor prescribes and any over the counter drugs you take?

Monthly Amount: $__________

10. Have any of your family members (mother, father, brother, sister or children):
    - Been on dialysis? □ Yes □ No □ Not Sure
    - Had a kidney transplant? □ Yes □ No □ Not Sure
    - Had other kidney problems? □ Yes □ No □ Not Sure

11. When were you first diagnosed with kidney disease?

    Month ________     Year _______________

12. Where were you first diagnosed with kidney disease? Please check one
    □ Hospital
    □ Emergency Room
    □ Primary care doctor’s office (family doctor)
    □ Kidney doctor’s office
    □ Other doctor’s office
    □ Other

13. What stage of kidney disease did you have when you were diagnosed? Please check one
    □ Stage 1
    □ Stage 2
    □ Stage 3
    □ Stage 4
    □ Stage 5
    □ Not sure

14. How would you rate your quality of life most days? Please check one
    □ Poor
    □ Fair
    □ Good
    □ Excellent

15. How many times in the past year have you been in the hospital?

    _________ number of times

16. What kind of dialysis treatment do you use now? Please check one
    □ In-center hemodialysis—traditional (3 days a week)
    □ In-center hemodialysis—nocturnal (night-time)
    □ In-center hemodialysis—frequent (more than 3 days a week)

17. When do you receive dialysis treatment? Please check one
    □ Monday, Wednesday, Friday
    □ Tuesday, Thursday, Saturday
    □ Other ____________________________

18. What time of day do you receive your treatment? Please check one
    □ Morning
    □ Mid-day
    □ Evening
    □ Night
19. Has your kidney doctor talked to you about the choice of peritoneal dialysis? Please check one
- No
- Yes
- Not Sure

20. Has your kidney doctor talked to you about the choice of home hemodialysis? Please check one
- No
- Yes
- Not Sure

21. What type of dialysis access do you have? Please check all that apply
- AV Fistula
- Graft
- Catheter
- Peritoneal dialysis center

22. Have you ever used a different type of dialysis treatment in the past? Please check one
- No (skip to question 23)
- Yes
  - What other types of dialysis have you used? Please check all that apply
    - In-center hemodialysis – traditional (3 days a week)
    - In-center hemodialysis – nocturnal (night-time)
    - In-center hemodialysis – frequent (more than 3 days a week)
    - Peritoneal dialysis – CAPD (continuous ambulatory peritoneal dialysis)
    - Peritoneal dialysis – CCPD (continuous cycling peritoneal dialysis)
    - Home hemodialysis – traditional (3 days a week)
    - Home hemodialysis – frequent (more than 3 days a week)
    - Home hemodialysis – nocturnal (night-time)

23. Have you ever had a kidney transplant? Please check one
- No (skip to question 24)
- Yes
  - If yes, how many kidney transplants have you had? Please specify
    ______________ number of kidney transplants
  - How many years did the most recent transplant work? Please check one
    - Less than 1
    - 1—2 years
    - 3—5 years
    - More than 5 years

24. Are you currently on the transplant list? Please check one
- Yes (skip to question 25)
- No
  - If no, has your kidney doctor talked to you about the choice of transplant? Please check one
    - No (skip to questions 25)
    - Yes
      - If yes, has your doctor ever talked to you about the option of transplant with a living donor? Please check one
        - No
        - Yes

25. What year did you start dialysis? ________________
26. Which best describes when you started dialysis? Please check one
- I started dialysis right away (within 3 months of first seeing a kidney doctor)
- I started dialysis between 3 months and 1 year of first seeing a kidney doctor
- I started dialysis 1-2 years after first seeing a kidney doctor
- I started dialysis more than 2 years after first seeing a kidney doctor
- I had never seen a kidney doctor before I started dialysis

27. Please circle your agreement from 1-5 with “1” being “Strongly Disagree” and “5” being “Strongly Agree” for each of the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being on dialysis has not changed the way I go about my day</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I have learned how to manage my life well on dialysis</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I no longer enjoy doing many of the things I used to do before dialysis</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I have had to stop working since I started dialysis</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I have had a very hard time getting used to my life on dialysis</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I have had a lot of pain since I started dialysis</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I feel too sick most of the time to enjoy my life</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>My relationships with friends and family have become strained since I</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>started dialysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being on dialysis has not affected my personal relationships</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I need help now doing many of the things that I was able to do alone</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>before dialysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel depressed or sad many days</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

28. How did you decide which dialysis center to go to? Please check one
- Close to my house
- Close to my work
- Close to my doctor
- My doctor chose
- Other ____________________________

29. Have you ever received dialysis at a different dialysis center for a long period of time (not including hospital visits or a trip you took)?
- No (skip to question 30)
- Yes
  - If yes, Why did you change dialysis centers? Please check one
    - To be closer to my house
    - I changed doctors
    - My doctor moved to a different dialysis center
    - Insurance reasons
    - I was not happy with the care I was getting
    - Other ____________________________

30. Have you ever had a different kidney doctor? Please check one
- No
- Yes

31. Do you always see the same kidney doctor or do different kidney doctors check on you while you are on dialysis?
- Please check one
  - See only one kidney doctor
  - See different kidney doctors
32. How often do you see the following types of doctors? Please indicate how often by placing an “X” in the appropriate box.

<table>
<thead>
<tr>
<th>Type of doctor</th>
<th>Never</th>
<th>Once a year</th>
<th>Twice a year</th>
<th>More than twice a year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care doctor (family doctor)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiologist (heart doctor)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Endocrinologist (diabetes doctor)</td>
<td></td>
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<tr>
<td>Urologist</td>
<td></td>
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<td></td>
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<tr>
<td>Hematologist (blood doctor)</td>
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<tr>
<td>Gastroenterologist (stomach doctor)</td>
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<td></td>
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<tr>
<td>Gynecologist</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

33. What is the cause of your kidney disease? Please check all that apply

- Diabetes (sugar in my blood)
- Hypertension (high blood pressure)
- Polycystic kidney disease
- Other ____________________________________

34. Have you ever heard of the medicines listed below? Please indicate your answer by placing an “X” in the appropriate box if you have heard of the medicine.

<table>
<thead>
<tr>
<th>Epogen</th>
<th>Aranesp</th>
<th>Procrit</th>
<th>Venofer</th>
<th>Ferrlecit</th>
<th>Feraheme</th>
<th>Hectorol</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zemplar</td>
<td>Sensipar</td>
<td>Renagel</td>
<td>Renvela</td>
<td>PhosLo</td>
<td>Fosrenol</td>
<td>Lipitor</td>
</tr>
</tbody>
</table>

35. How satisfied are you with the care you receive as a dialysis patient? (Please circle your response using a scale of 1-7 where “1” is “Not at all Satisfied” and “7” is “Extremely Satisfied”)

1 2 3 4 5 6 7

36. How satisfied are you with your dialysis center? (Please circle your response using a scale of 1-7 where “1” is “Not at all Satisfied” and “7” is “Extremely Satisfied”)

1 2 3 4 5 6 7

37. How satisfied are you with each of the following people who care for you? Please circle how satisfied you are from 1-7 with “1” being “Not at all Satisfied” and “7” being “Extremely Satisfied”

<table>
<thead>
<tr>
<th>Person who cares for you</th>
<th>Not at all Satisfied</th>
<th>Extremely Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your kidney doctor</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>The Nurses at your dialysis unit</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>The Dietician at your dialysis unit</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>The social worker at your dialysis unit</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>The technician at your dialysis unit</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>
38. What is the one thing at your dialysis center you are least satisfied with? Please chose one

- No shift flexibility
- Transportation to unit
- Cleanliness of unit
- Dialysis unit staff
- Patient mix
- Other ______________________________________________________

39. What do you usually do when you are on dialysis? Please check all that apply

- Read
- Sleep
- Watch TV (entertainment)
- Watch TV (educational)
- Listen to music
- Talk with patients
- Talk with staff
- Other ______________________________________________________

**Dialysis / Medication Questions**

40. Have you missed any dialysis sessions in the past month?

- No (skip to question 41)
- Yes

If yes, how many sessions have you missed? __________

What are the reasons you missed a dialysis session or sessions?

Please check all that apply

- I didn’t have a ride to the dialysis center
- I was in the hospital
- I didn’t feel well
- I felt well so I thought it was okay to skip a session
- Other reason ______________________________________________________

41. How many different drugs do you take by mouth? __________________________

42. What is the total number of pills you take each day? _________________________

43. Where would you want to get your drugs that you take by mouth? Please check one

- Local pharmacy / drug store
- My dialysis center
- Mailed to my house
- Other ______________________________________________________

44. Are you taking a phosphate binder now? Please check the phosphate binder(s) you are on

- Fosrenol
- Renagel
- Renvela
- PhosLo or any other calcium acetate
- Tums or any other calcium carbonate
- No (skip to question 51)
- Not sure (skip to question 51)
For patients on phosphate binders:

45. Do you ever forget to take your phosphate binder?
   - No (skip to question 46)
   - Yes
     - If yes, how often do you forget to take your phosphate binder?
       - Rarely
       - Sometimes
       - Often

46. Do you ever take a smaller amount of your phosphate binder than your kidney doctor prescribes?
   - No (skip to question 47)
   - Yes
     - If yes, How often do you take a smaller amount of your phosphate binder?
       - Rarely
       - Sometimes
       - Often

47. How often do you forget to take your phosphate binder or take less than what your doctor prescribes because of the reasons listed below? Please indicate your response by placing an “X” in the appropriate box.

<table>
<thead>
<tr>
<th>Reasons for not taking phosphate binder</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>To save money</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The pills make me feel badly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The pills taste bad or are hard to swallow</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t like taking so many pills</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I forget to take them with me when I go out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t feel sick so I don’t think I need to take them</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

48. How bad are the side effects with your phosphate binder? Please circle your response using a scale of 1-7 where “1” is “Not bad at all” and “7” is “Very bad”

1  2  3  4  5  6  7

49. If you were unhappy with the way your phosphate binder tasted or made you feel, who would you most likely talk to about it? Please check one
   - Kidney doctor
   - Nurse
   - Dietician
   - Pharmacist
   - Social Worker
   - Family member / friend
   - Another patient
   - I wouldn’t talk about it
   - Other ________________________________________________

50. How would you prefer to take your phosphate binder? Please check one
   - Tablets to swallow
   - Capsules to swallow
   - Tablets to chew
   - Liquid to drink
   - Powder to sprinkle on my food
   - Powder to mix with a drink
All Patients:

51. Do you take Sensipar?
   - No (skip to question 52)
   - Not Sure (skip to question 52)
   - Yes

   If yes, do you ever forget to take Sensipar or take less than what your kidney doctor prescribes?
   - No
   - Yes, how often?
     - Rarely
     - Sometimes
     - Often

52. Do you take any of the following? Please check one
   - Aranesp
   - Epogen
   - Procrit
   - None (skip to question 54)
   - Not sure (skip to question 54)

For those on Aranesp, Epogen, or Procrit:

53. Does the nurse at the dialysis center give you a shot of your Epogen/Aranesp/Procrit or is it given through your dialysis (through a vein in your arm)? Please check one
   - Shot under my skin (skip to question 54)
   - Through dialysis (vein in my arm)

   If you receive your Epogen / Aranesp / Procrit through a vein in your arm, how would you feel if your doctor told you that you would need to take Epogen / Aranesp / Procrit in a shot (under your skin)? Please circle your response using a scale of 1—7 where “1” is “I would not like that at all” and “7” is “It would not bother me at all”

   1  2  3  4  5  6  7

All Patients:

54. If you could not pay for all of your prescriptions in one month, which drugs would you be most likely to skip?

___________________________________________________________________________________________

55. Please check which drugs you are on. Then, for the drugs you are on, rank order their importance by giving a 1 to the drug you think is most important, a 2 to the second most important drug, until all the drugs you take that are listed below have a number.

<table>
<thead>
<tr>
<th>Check if on</th>
<th>Rank Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Phosphate binder (For example: Fosrenol, PhosLo, Renagel, Renvela)</td>
<td>□</td>
</tr>
<tr>
<td>B. High blood pressure drug</td>
<td>□</td>
</tr>
<tr>
<td>C. Cholesterol lowering drug</td>
<td>□</td>
</tr>
<tr>
<td>D. Anemia drugs (For example: Procrit, Aranesp, Epogen, Venofer, Ferrlecit, Feraheme)</td>
<td>□</td>
</tr>
<tr>
<td>E. Insulin / diabetes drug</td>
<td>□</td>
</tr>
<tr>
<td>F. Vitamin D (For example: Hectorol, Zemplar, Calcitriol)</td>
<td>□</td>
</tr>
<tr>
<td>G. Gout drug (For example: Allopurinol, Uloric)</td>
<td>□</td>
</tr>
<tr>
<td>H. Sensipar</td>
<td>□</td>
</tr>
</tbody>
</table>
56. Which drugs, if any, were you on before you started dialysis? Please indicate which drugs you were on before starting dialysis by placing an “X” in the appropriate box.

<table>
<thead>
<tr>
<th>Type of drug</th>
<th>No</th>
<th>Yes</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phosphate binder (For example: Fosrenol, PhosLo, Renagel, Renvela)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High blood pressure drug</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cholesterol lowering drug</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anemia drugs (For example: Procrit, Aranesp, Venofer, Ferrlecit, Feraheme)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Vitamin D (For example: Hectorol, Zemplar, Calcitriol)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gout drug (For example: Allopurinol, Uloric)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

57. How do you like to learn about kidney health?
   Please check all that apply
   - Internet (web)
   - Printed materials
   - Video or DVD
   - Small live groups
   - Telephone
   - Audio tapes
   - My healthcare professional (doctor, nurse, social worker, etc)

58. Do you keep track of your important numbers (lab values)? Please indicate how often by placing an “X” in the appropriate box

<table>
<thead>
<tr>
<th>Lab value</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood pressure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cholesterol</td>
<td></td>
<td></td>
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<tr>
<td>Insulin</td>
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<tr>
<td>Hemoglobin</td>
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<td></td>
</tr>
<tr>
<td>Phosphorus</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Calcium</td>
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<tr>
<td>PTH</td>
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<tr>
<td>TSAT</td>
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<td></td>
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<tr>
<td>Ferritin</td>
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</tr>
</tbody>
</table>

59. Do you have internet (web) access? Please check one
   - No
   - Yes
60. How often do you get information about kidney disease from the following sources? Please indicate by placing an “X” in the appropriate box.

<table>
<thead>
<tr>
<th>Source</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney doctor</td>
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<td></td>
</tr>
<tr>
<td>Other doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Pharmacist</td>
<td></td>
<td></td>
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<tr>
<td>National Kidney Foundation (NKF)</td>
<td></td>
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<tr>
<td>American Association of Kidney Patients (AAKP)</td>
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<tr>
<td>American Kidney Fund (AKF)</td>
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<td></td>
</tr>
<tr>
<td>Other patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family members / friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mail to my home</td>
<td></td>
<td></td>
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<tr>
<td>Booklets / materials given to me in the dialysis unit</td>
<td></td>
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</tr>
<tr>
<td>Internet, which sites?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
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61. Have you been able to get the information you need about kidney health? Please check one
☐ No
☐ Yes

62. Have you been able to get enough helpful information that you can understand about:

A. Hyperphosphatemia (phosphorous is a mineral important to your bone health)
   ☐ No        ☐ Yes

B. High PTH (a hormone that helps your bones stay healthy)
   ☐ No        ☐ Yes

C. Anemia (low red blood cell count)
   ☐ No        ☐ Yes

63. Would you find it helpful to have another dialysis patient to talk with about your kidney disease?
☐ No
☐ Yes

64. Have you received any money / financial aid, coupons or free drugs from any of the following?

AAKP     ☐ No        ☐ Yes
AKF      ☐ No        ☐ Yes
NKF      ☐ No        ☐ Yes
Dialysis center ☐ No        ☐ Yes
Pharmaceutical company ☐ No        ☐ Yes
Other:   ☐ No        ☐ Yes

65. What advice would you give other people who are starting on dialysis?

____________________________________________________________________________________________
____________________________________________________________________________________________

Thank You!