PATIENTS’ Rights
■ Quality Care
■ Information
■ Individual Treatment
■ Privacy and Confidentiality
■ Services Without Discrimination
■ Treatment Options
■ Kidney Transplantation
■ Home Care
■ Self-Care Treatment
■ Emergency Care
■ Dietary Counseling
■ Social Work Services
■ Facility Management
■ Formal Complaint Process
■ Refusal and Advance Directives
■ Medical Consultation
■ Research Programs
■ Treatment Costs

PATIENTS’ Responsibilities
■ Be Informed
■ Plan and Follow a Treatment Program
■ Be on Time
■ Follow Facility Policies
■ Be Considerate
■ Fulfill Financial Obligations
Your Rights

1. Quality Care
You have the right to:

■ Receive high-quality health care that meets recognized professional goals.

■ Be part of the health care team, along with a social worker, nurse, doctor and dietitian.

■ Expect that staff members in training will be directly supervised.

2. Information
You have the right to:

■ Receive information from your nephrologist (kidney doctor) in words that you can understand. This should include information about your medical conditions, treatment choices, test results and possible problems. If this information cannot be given to you directly, the doctor should speak to your family or the person acting on your behalf.
■ Be informed about current dialysis treatments for kidney disease.
■ Be informed of the process of dialyzer re-use and your options.
■ Receive a complete review of any test results and treatment by your doctor or a member of the health care team.
■ Be informed of any possible side effects of medications you are taking.

3. Individual Treatment
You have the right to:
■ Be treated with dignity, respect and consideration.
■ Suggest a change in the type of treatment.
■ Expect your kidney doctor and other members of your health care team to listen to you when you suggest changes in your dialysis treatment.
■ Expect that treatment will be tailored to your individual health needs.
■ Expect that the patient-to-staff ratio at your facility conforms to state regulations.

4. Privacy and Confidentiality
You have the right to:
■ Expect privacy when receiving medical care.
■ Expect examinations and discussions about your care to be held in private.
■ Expect that your personal medical information will be kept confidential.

5. Services Without Discrimination
You have the right to:
■ Expect medical care without regard to your race, color, gender, sexual preference, religion or national origin.
6. Treatment Options
You have the right to:

■ Receive a full explanation of all treatment options for kidney disease, including their advantages and disadvantages.

7. Kidney Transplantation
You have the right to:

■ Receive a full explanation of the kidney transplant process including all transplant options.

■ Select the transplant center at which you desire to have a transplant evaluation after consultation with the nephrologist.

8. Home Care
You have the right to:

■ Be informed of new advances in home care and have the opportunity to make a change to that treatment option.

■ Receive educational materials about new procedures.

■ Suggest changes in your home care treatment.

■ Receive follow-up care by dietary, social work and nursing services.
9. Self-Care Treatment
You have the right to:

- Receive information about dialysis facilities that offer self-care.

10. Emergency Care
You have the right to:

- Receive emergency medical care without unnecessary delay.
- Be informed by the dialysis facility about their emergency plan in case of a disaster (e.g., snow storm, fire, loss of power).
- Be informed of the facility’s plan of action in case of medical emergencies.
11. Dietary Counseling
You have the right to:

■ Receive counseling from a qualified dietitian according to federal and state law.
■ Receive nutritional educational material and instruction.
■ Receive care and counseling on a regular basis.

12. Social Work Services
You have the right to:

■ Receive counseling from a qualified social worker according to federal and state law.
■ Receive an evaluation and follow-up care, including a vocational rehabilitation review.
■ Receive referrals to community services when needed.

13. Facility Management
You have the right to:

■ Expect the dialysis facility to employ skilled staff and provide safe, clean, comfortable and professional surroundings.
■ Expect the facility to make every effort to make you comfortable and give you your treatment on time, according to a schedule that meets special needs whenever possible.
■ Expect the facility to monitor the quality of treatment and equipment according to regulations.

14. Formal Complaint Process
You have the right to:

■ Make a complaint to your facility management and request that they try to resolve a problem.
■ Ask and be instructed on your dialysis facility’s grievance process.
■ File a complaint with the End-Stage Renal Disease Network in the region, and/or your state health department in an attempt to resolve a problem.
15. Refusal, Advance Directives and End-of-Life Care
You have the right to:

- Make decisions about your health care based on information given to you by your kidney doctor.
- Complete an advance directive stating your wishes.
- Be informed by your kidney doctor of the possible results of refusing drugs, treatments or procedures.
- Be informed of how the facility cares for those regarding end-of-life needs.
- Refuse any drugs, treatments or procedures offered to you.
- Indicate your refusal in writing.
- Accept full responsibility for the medical outcomes of your refusal.

16. Medical Consultation
You have the right to:

- Request consultation with another doctor for any kidney- or non-kidney-related medical problem.
- Know that payment for consultation may not be covered under Medicare or other health care coverage, and you may be responsible for payment.

17. Research Programs
You have the right to:

- Receive a full explanation of any research program in which you may be able to participate.
- Know that the study will not be conducted without your informed consent or that of the person acting on your behalf.
- Refuse or withdraw from the research study at any time.
18. Treatment Costs
You have the right to:

■ Receive a full explanation of all charges by the facility and doctor.
■ Be informed about your financial responsibilities after Medicare or Medicaid and/or other health care insurance coverage.
■ Obtain assistance with completing insurance forms.
■ Get information about how you can pay your bill and about programs available to help you.

Your Responsibilities

1. Be Informed
It is your responsibility to:

■ Learn as much as you can about your kidney disease and how it is treated.
■ Talk to your health care team about your concerns regarding your treatment.

2. Plan and Follow a Treatment Program
It is your responsibility to:

■ Supply all information about your health needed to plan and carry out a treatment program that will give you the best results.
■ Find out about the other services and referrals that are recommended by your health care team.

3. Be On Time
It is your responsibility to:

■ Make every effort to be on time for your scheduled dialysis.
■ Tell the dialysis facility ahead of time if you are unable to attend your next treatment date.
■ Understand that your treatment time may be shortened if you arrive late.

4. Follow Facility Policies
It is your responsibility to:

■ Follow the facility policies and procedures that have been developed to provide safety and quality of care to all patients.

5. Be Considerate
It is your responsibility to:

■ Treat other patients and staff members with respect, dignity and consideration.

■ Never threaten others, act in a violent manner or cause any physical harm.

6. Fulfill Financial Obligations
It is your responsibility to:

■ Make every effort to pay your bills for care from the dialysis facility and doctor(s).

■ Obtain Medicare Part B coverage or co-insurance through a private carrier.

■ Inform the facility business office of all health insurance programs and policies from which you receive direct payment for services in the treatment of kidney disease.

■ Pay the dialysis facility and doctor when you receive payments from your health insurance company or medical policies.
Many thanks to the following organizations for their role in assisting with the development of the Dialysis Patients’ Bill of Rights and Responsibilities

| American Society of Transplantation          | NKF Council on Renal Nutrition               |
| Centers for Medicare & Medicaid Services    | NKF Council of Nephrology                   |
| ESRD Network 4                              | Nurses and Technicians                       |
| ESRD Network 7                              | NKF Patient & Family Council                |
| ESRD Network 8                              | Executive Committee                          |
| ESRD Network 13                             | National Renal Administrators Association    |
| ESRD Network 18                             | Renal Physicians Association                 |
| NKF Council of Nephrology                   | TransPacific Renal Network                   |
| Social Workers                              |                                            |
More than 20 million Americans—one in nine adults—have chronic kidney disease, and most don’t even know it. More than 20 million others are at increased risk. The National Kidney Foundation, a major voluntary health organization, seeks to prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation. Through its 47 affiliates nationwide, the foundation conducts programs in research, professional education, patient and community services, public education and organ donation. The work of the National Kidney Foundation is funded by public donations.

The Patient & Family Council (PFC), founded in 1995, is the largest patient group dedicated to supporting, serving and advocating for people with kidney disease. Providing a strong voice in the community and in Congress, the advocacy efforts of the PFC help improve the lives of thousands of people affected by kidney disease.

Kidney Learning Systems (KLS)™

A Curriculum for CKD Risk Reduction and Care

Light-shaded boxes indicate the scope of content in this KLS resource. GFR = Glomerular Filtration Rate; T = Kidney Transplant; D = Dialysis

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