RENNEDY KRIEGER INSTITUTE Patient Bill of Rights and Responsibilities

Kennedy Krieger Institute recognizes and respects the rights of patients and their families. At Kennedy Krieger, we ground our care and services in treating others with respect and civility. We acknowledge the cultural identity of each person. We educate and inform patients and families about care provided in the best interest of the patient's health and well-being while aiming to respect cultural, psychosocial, spiritual and personal values, beliefs and preferences. Further, we strive for equitable care. We encourage patients and families to become active partners in their care by asking questions, seeking resources and advocating for their needs. These rights and

responsibilities are extended to the patient, the patient's family and other persons served. Here, "family" refers to parents, other family members, guardians, surrogate decision-makers and healthcare agents.

If you experience a medical emergency while at Kennedy Krieger, a prompt and safe transfer to a higher level of care will be arranged, when necessary.

You have the right to...

Respectful and safe care.

- You will receive respectful, considerate and compassionate care in a safe setting.
- Kennedy Krieger Institute does not discriminate against people based on, but not limited to, perceived or actual: race, color, culture, ethnicity, national origin, age, language spoken, accent, marital status, veteran or military status, immigration status, socioeconomic status, physical or mental disability, religion, pregnancy status, sex, sexual orientation, or gender identity or expression.
- You will be:
 - Told if something goes wrong with your care.
 - Free from verbal, mental, physical or sexual abuse, neglect or mistreatment.
 - Provided access to protective and advocacy services. For questions, information and resources, contact the Social Work Department at **443-923-2800**.
 - Free from restraints and/or seclusion unless needed emergently or for safety.

Get important information about your care.

This right includes communicating information:

- In a way that you can understand.
- That meets your individual needs related to language, vision, speech, hearing or other conditions. This includes communication assistance, such as sign language and foreign language interpreters, as well as vision, speech and hearing assistance, provided free of charge.

Participate in your care.

- You—and your family and friends, with your permission—can participate in decisions about your care, treatment and services.
- You can refuse treatment to the extent permitted by law. If you refuse care, we may suggest other ways of treating you and still continue to see you or refer you to another provider to get care.
- You will have your pain screened, assessed and managed.

- Inpatients can choose and receive visitors, such as family members, friends or others.
 - You will be asked to provide a list of visitors; this list can be changed at any time.
 - We can restrict visitation rights in order to comply with state and local guidelines during a pandemic or if the visitor interferes with your and others' rights, safety or care.

Make informed decisions about your care.

- The informed consent process involves a discussion about your proposed care, treatment and services; potential benefits, risks and side effects; likelihood of reaching your goals; any potential problems that might occur; and reasonable alternatives (including benefits and risks to alternatives).
- You can choose or refuse to take part in research.
 - You will get information about the research purpose and procedures; expected duration of participation; potential benefits, risks, discomforts and side effects; and alternative care, treatment and services.
 - If you join a research study, you can withdraw from it at any time.
 - If you refuse to take part, your clinical care will not be affected.

Make or change an Advance Directive for Health Care or an Advance Directive for Mental Health Treatment according to Maryland law if you are 18 years or older.

- You can appoint someone to make healthcare decisions for you if you are unable to do so.
- If you do not have an advance directive, we can provide you with information and help you complete one. Contact the Social Work Department at **443-923-2800** for assistance.

Know the names and roles of the members of your healthcare team.

- Your treatment team coordinates your care throughout Kennedy Krieger Institute.
- You may refuse observations by others not directly involved in your care.

Your responsibilities:

We expect you and your family members to interact in an honest, respectful and responsible manner and to follow hospital rules, instructions and financial commitments. Mutual respect supports communication and collaboration in a manner that contributes to the safety and quality of care, treatment and services. These expectations are for those who receive services on-site or via telehealth. It is important that you:

- Speak openly with your healthcare team.
- Share complete and accurate information about your health, healthcare coverage and any other requested information.
- Ask questions if there is anything that you do not understand.
- Follow your treatment plan.
- Show consideration for hospital staff members and other patients, including their families and their belongings.
- Pay for any services for which you are responsible.

Privacy and confidentiality.

- You will be offered and given (according to personal preference) a copy of the HIPAA Notice of Privacy Practices, which includes information about how to access your medical record.
- Full consideration of your privacy and confidentiality will be provided during care discussions, exams and treatments.
- All communication and medical records about your care will be kept confidential.
- Sometimes, disclosure of healthcare information is permitted by law.
- You will be asked to provide a list of names and addresses of those with whom you want to share your health information; this list can be changed at any time.
- You can agree or refuse to allow taking or using pictures, videos or recordings if they are not required for your care.

See and get a copy of your medical record.

- Upon request, your provider will review your record with you.
- If you think that important information is missing or wrong, then you may ask to amend the record according to Maryland law.
- If you would like a copy of your report, visit **ReleaseOfInformation@KennedyKrieger.org** or contact the Health Information Management Department at **443-923-1825**.

Receive information about hospital and physician charges and ask for an estimate of hospital charges before care is provided, and as long as care is not delayed.

Consult with the Ethics Program regarding challenging decisions about your care, treatment and services.

• Contact the Ethics Program at **443-923-7686** for more information.

- Give us a copy of your advance directive or ask for help with writing one.
- Be on time for appointments and call as soon as possible if you need to cancel.
- Respect the privacy of others by not sharing information and conversation seen or heard.
- Do not make videos or recordings or take pictures of other children or their family members, or of staff members. This includes social media posts and photos and videos of others shown in the background.
- Leave valuables at home.

Speak with a staff member or supervisor if you are concerned with any aspect of your care.

- Contact the Office of Patient Experience and Community Engagement at **443-923-2640** for additional help.
- If you voice your concern and recommend changes, your care will not be affected.
- If you have exhausted all hospital resources and continue to have a concern that the hospital has not resolved to your satisfaction, you may also contact:

Maryland Department of Health

Office of Health Care Quality 7120 Samuel Morse Drive Second Floor Columbia, MD 21046 410-402-8015 or TTY: 800-735-2258

https://health.maryland.gov/ohcq/Pages/home.aspx

The Joint Commission

Office of Quality and Patient Safety 1 Renaissance Boulevard Oakbrook Terrace, IL 60181

https://www.jointcommission.org/resources/patientsafety-topics/report-a-patient-safety-event/

