

Research Participant's Bill of Rights

As a participant in a research study/clinical trial, you have the right:

- 1. To be told **why** the study is being conducted.
- 2. To be told **who** is funding the study.
- 3. To be given an explanation of **what will happen** during the study, what is expected of you, and **what will be different** from non research medical treatment.
- 4. To be given an explanation of any **risks or discomforts** that may be experienced from participating in the study.
- 5. To be given an explanation of any **benefits** that may be expected from participating in the study.
- 6. To be told, if treatment is part of the study, of other **non-research treatment choices** that are available and how they compare to participating in the study.
- 7. To be given the opportunity to **ask questions** about the study or about participating in the study, before agreeing to participate and during the course of the study.
- 8. To be told of your **right to refuse** to begin the study, or to change your mind and stop participating in the study after it has started. Your participation is completely voluntary. If treatment is part of the study, this decision will not affect your ability to receive non research treatment.
- 9. To be told that you may refuse to answer any question.
- 10. To have enough **time to decide** whether or not to participate and to make that decision without any pressure from the people who are doing the research.
- 11. To be told, if treatment is part of the study, whether there are **any costs** to you associated with being in the study and whether you will receive any reimbursement for participating in the study.
- 12. To be told **who will have access** to information collected about you, how the information will be used, and how the confidentiality of your information will be protected.
- 13. To be told **who to contact directly** with questions about the research, about research related injury, and about your rights as a research participant.
- 14. To be told, if the research is greater than minimal risk, whether any compensation and medical treatments are available should you have a research related injury, what the treatments are, and where further information may be obtained.
- 15. To be **told about new information** learned during the study that might affect your safety or your willingness to continue to take part in the study.
- 16. To receive a copy of the consent form if one is part of the study.