

Forgotten Diseases Research Foundation

Research Subject's Bill of Rights

The rights below belong to every person who is asked to be in a research study. As a research subject I have the following rights:

1. To be told what the study is trying to accomplish/learn;
2. To be told what will happen to me;
3. To be told about the frequent and/or important risks, side effects, or discomforts of the things that will happen to me for research purposes;
4. To be told if I can expect any benefit from participating, and, if so, what the benefit might be;
5. To be told of the other choices I have and how they may be better or worse than being in the study;
6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study;
7. For studies involving medical interventions, be told what sort of medical treatment is available if any complications arise;
8. To refuse to participate at all or to change my mind about participation after the study has started. This decision will not affect my right to receive the care I would receive if I were not in the study;
9. To receive a signed and dated copy of the consent form;
10. To be free of pressure when considering whether I wish to agree to participate in the study.
11. I may contact Dr. Natale at +1-408-529-5755 (phone) via e-mail at vnatale@forgottendiseases.org. Her mailing address is 604 Malarin Ave., Santa Clara, CA 95050 USA.

If I have other questions I should ask Dr. Natale. I may reach her by calling, faxing, or writing to the address included with this document. The best times to call are between 9:00 a.m. and 6:00 p.m., Monday to Friday (Pacific time).