



INFORMED CONSENT to PERFORM GENETIC TESTING FOR RETINOBLASTOMA

I, _____, consent to participate, or as applicable, to have my child _____ participate, in a DNA-based test to identify an abnormality in the retinoblastoma gene (*RB1* gene). I understand this test requires a blood sample from the person to be tested and in some cases, a fresh tumor sample, and may require blood samples from other people related by blood. I understand that the blood and tumor samples will be used to determine if the subject and the subject's relatives carry a genetic abnormality believed to cause retinoblastoma tumors.

By signing below, I acknowledge that:

1. My participation and as applicable, my child's participation, in this DNA testing is voluntary.
2. The removal of up to 10 ml of blood (5 ml for infants) required for the test carries a low risk of discomfort and infection.
3. Although the lab makes every effort to ensure the accuracy of test results, there remains a small possibility of human error and a very small chance that there exists in the subject's DNA a second mutation not identified by the test. Consequently, a remote but real possibility remains that the DNA test results lead to an inaccurate diagnosis.
4. A person whose DNA contains a genetic abnormality associated with retinoblastoma does not necessarily develop the disease. A negative test result does not imply that the subject has no chance to develop retinoblastoma.
5. All test results are confidential; no information will be printed or released that discloses the patient's identity without my additional written permission. Only the referring physician I designate on the Retinoblastoma Requisition Form will receive a written report of test results.
6. *Retinoblastoma Solutions* is not a DNA banking facility and patient DNA samples may not be available for future testing.
7. An error in diagnosis may occur if the true biological relationships of the family members are not as stated in the pedigree submitted with the Retinoblastoma Requisition Form. It is possible that the test may disclose paternity and I consent that this finding be reported to the physician designated on the Retinoblastoma Requisition Form.
8. Until the results of this test are reported, the patient and members of the patient's family should still undergo retinal examinations as prescribed by my physician.
9. My referring physician reviewed this consent form with me, point by point, and explained the implications of the test results to me. Any questions that I asked have been answered to my satisfaction. I know that I (or members of my family) may ask any questions we have about the collection, use and disclosure of our personal genetic information.
10. If necessary to obtain reimbursement of test fees, *Retinoblastoma Solutions*, its agents and legal representatives may disclose information that identifies me or my children who are subject to *RB1* genetic testing.
11. I received a copy of this consent form and the referring physician whom I designate on the Retinoblastoma Requisition Form received a copy of this consent form.
12. *Retinoblastoma Solutions* has my consent to use the subject's DNA in an anonymous fashion for research to improve the sensitivity of *RB1* genetic tests.

 Signature of Subject or Consenting Parent

 Date

Statement of Referring Physician: I reviewed this form with my client, point by point. I offered to answer any questions regarding personal genetic information for the client or the client's children.

 Signature of Referring Physician

 Date