



## ISTITUTO C.S.S. MENDEL

Unità di Neurogenetica

Viale Regina Margherita, 261 - 00198 Roma

Tel. 06/44160537 Fax 06/44160548 Email: [e.valente@css-mendel.it](mailto:e.valente@css-mendel.it)

### JOUBERT SYNDROME RESEARCH PROJECT INFORMED CONSENT FORM

We \_\_\_\_\_ and \_\_\_\_\_  
parents of \_\_\_\_\_  
agree to participate to the study "Molecular characterization of Joubert syndrome",  
currently ongoing at the CSS-Mendel Institute in Rome. The aims and procedures of  
the study have been illustrated to us in detail by Dr. Enza Maria Valente.

We are aware that:

1. The goal of the study is to achieve a better knowledge of the genetic contribution to Joubert syndrome and related disorders;
2. There are no expected benefits to individual subjects in the short term;
3. The study does not involve experimental pharmacological treatments or invasive diagnostic procedures;
4. The study is based on clinical examination and collection of a blood sample (10 ml) from us and our child/children, to be used for research purposes only;
5. We can withdraw from the study at any time without jeopardizing future treatment by physicians or facility involved;
6. The study has no cost and complete confidentiality on clinical and laboratory data will be maintained.

Signature 1 \_\_\_\_\_

Printed name : \_\_\_\_\_

Signature 2 \_\_\_\_\_

Printed name : \_\_\_\_\_

Physician's signature \_\_\_\_\_

Printed name : \_\_\_\_\_

Witness' signature \_\_\_\_\_

Printed name : \_\_\_\_\_

Date \_\_\_\_\_