INFORMATION TO THE PARTICIPANT
For susceptibility testing
in Clinical Research

1. **Project Title**

   Influence of Genetic and Epigenetic Factors on Susceptibility to Retinopathy of Prematurity and its Progression

2. **Description of the project, its nature and objective**

   Preterm infants, especially those who are born before the 32nd week of gestation or with birth weight of less than 1500g, are at risk of developing a disease, retinopathy of prematurity, which affects the vessels of the retina (ocular fundus). The aim of this study is to determine genetic causes that may contribute to the onset and progression of this disease. Inclusion in the study does not change the follow-up or medical care to be provided to infants in the Neonatology Unit. To participate, it is necessary to carry out an examination of the mother and the infant, which consists of gently passing a colletion swab on the inner part of the cheek. Also the blood left over after the routine laboratory tests performed to your baby may be used for the study. These samples will be used only for the study of the above-mentioned disease under this project. The data and results will be anonymous, not allowing the identification of patients participating in the study.

3. **Benefits**

   Current scientific knowledge does not allow us to assert the existence of any direct, immediate, or long-term benefit to your baby resulting from this investigation. However, there is a possibility that its results will contribute to a better understanding of the disease and/or its early identification.

   If the participant/legal guardians wish, the results of the tests (genetic study and circulating biomarkers) will be transmitted to them and if any genetic alteration is identified that is proven to be associated with the disease under study or to some genetic disease, will be carried out the medical report and suggested referral for genetic counseling.

4. **Serious risks and frequent risks**

   Participation in this study does not involve any type of risk or damage.

5. **Acknowledgements and identification of the principal researcher**

   The researcher, Mariza do Rosário Fevereiro Martins, ophthalmologist at Hospital CUF Descobertas in Lisbon, mobile phone +351-968260624, e-mail: mariza.martins@sapo.pt, or the person who asks for the consent, if different, thanks for the participation.

   The researcher remains at the disposal for any more detailed clarification on the ongoing research project, committing to provide the results at the end, if the participant/legal guardian so desires.