

Institute of Genetic Ocular in partnership with Retina São Paulo

Psychosocial Aspects of Genetic Ocular Diseases

Cecília Francini Cabral de Vasconcellos

Advisor: Prof. Dr. Mariana Valim Salles

This consent form refers to the project “Psychosocial Aspects of Genetic Ocular Diseases,” which includes five different studies. The parent group for children with genetic ocular diseases is study number 4.

São Paulo – july/2024

FREE AND INFORMED CONSENT FORM FOR RESEARCH IN A VIRTUAL ENVIRONMENT

You are being invited to participate in a research study. The title of the study is "Psychosocial Aspects of Genetic Ocular Diseases." The objective of this research is to assess the psychosocial impacts of genetic eye diseases (GED) on patients, family members, and caregivers. The researchers responsible for this study are Cecília Francini Cabral de Vasconcellos and Mariana Valim Salles.

You will receive all the necessary clarifications before, during, and after the completion of the research, and we assure you that your name will not be disclosed, with the strictest confidentiality maintained by omitting any information that would allow identification.

The information will be obtained in the following ways: mental health questionnaires, quality of life, or parental stress through the Google Forms platform; and/or initial interviews with patients, parents, family members, and caregivers; and/or group psychotherapy interventions.

Your participation involves the following minimal risks: engaging with experiences related to your visual impairment and recalling memories that may trigger certain emotions.

Your participation may help in understanding the psychosocial impacts of genetic eye diseases on patients, parents, family members, and caregivers. The benefits will include the creation of public policies for welcoming and addressing the psychosocial impacts of genetic ocular diseases.

Thus, you are being consulted about your interest and availability to participate in this study. You are free to refuse to participate, withdraw your consent, or interrupt your participation at any time. Refusal to participate will not result in any penalties.

If you decide to withdraw from the study, you may request the exclusion of the data collected at any time, with no consequences. To do so, please send an email to psicoceciliavasconcellos@gmail.com requesting the deletion of your collected data.

You will not receive payment for your participation. All information obtained through your participation will be used exclusively for this study and will be kept under the responsibility of the researchers. In the case of personal harm resulting from the research, compensation and indemnities as provided by law may be requested by the participant. The researchers may share the results of the research with you once it is completed, if you wish to know.

For more information about the rights of research participants, please read the "Research Participants' Rights Guide" prepared by the National Research Ethics Committee (Conep), which is available for reading on the website:

http://conselho.saude.gov.br/images/comissoes/conep/img/boletins/Cartilha_Direitos_Participantes_de

[Pesquisa_2020.pdf](#)

This study has been reviewed by a Research Ethics Committee (CEP). The CEP is responsible for evaluating and overseeing the ethical aspects of all research involving human beings to ensure the dignity, rights, and safety of research participants. If you have any questions and/or concerns regarding your rights as a participant in this study or if you are dissatisfied with how the study is being conducted, please contact the Research Ethics Committee (CEP) of the Hospital dos Olhos, located at R. Abílio Soares, 218 - Paraíso, São Paulo - SP, ZIP: 04005-000, São Paulo/SP, phone (11) 3050-3340.

If you have any doubts about the research, you can contact researcher Cecília through the following phone(s): (11) 983114036; email: psicoceciliavasconcellos@gmail.com; and address: Rua Fradique Coutinho, 776, Pinheiros - São Paulo.

If you agree to participate, please save and/or print this document in case you need this information in the future.

Participant's Consent

By selecting the "I Agree" option below, you declare that you understand the details of the research, that you have clarified any questions with the researchers, and that you accept to participate, knowing that you can withdraw at any time during or after participation. You authorize the disclosure of the data obtained in this study while keeping your identity confidential. We ask that you save this document and inform you that we will send a copy of this Consent Form to your email.

☐ I Agree

☐ I Do Not Agree

Researcher's Declaration

We declare that we have appropriately and voluntarily obtained the Free and Informed Consent of this participant (or legal representative) for participation in this study. We further declare that we are committed to fulfilling all the terms described herein.