HUMAN DEVELOPMENTAL GENETICS LABORATORY Medical College of Wisconsin, Children's Research Institute Elena Semina, PhD: 414-955-4996 Linda Reis, MS, CGC: 414-955-7645

Dear Participant(s):

You are being invited to participate in a research study called Genetic Studies of Human Ocular Disorders. You are being asked to participate because you or your child was born with an eye disorder. The goal of this study is to find out if there are genetic (inherited) differences between people with and without eye disorders. **This is a research study, which means we may or may not identify a genetic cause for your or your child's eye condition.** If we identify a genetic cause, this information may be useful in future family planning. Any person who was born with an eye disorder (or developed a disorder in early childhood) and his or her family can join this study. **There is no cost to participate in this study.**

Families willing to participate will meet or speak by telephone with Linda Reis, the study coordinator to discuss the study and complete enrollment. At this time, you will be asked to share information about your/your child's health. All information gathered from families is strictly confidential. You will also be asked to provide information about your family members to determine whether other people in your family might have the same condition. Your family members may enroll in this study if they want to. You can enroll even if your family members do not want to.

If you agree to participate, we will take a small sample of blood or saliva to obtain DNA, your genetic material. We request a small blood sample from each affected person and his/her parents (if available). At times, siblings of affected individuals may be invited to participate as well. We will analyze the DNA samples for possible causes of your or your relative's eye problems.

If you are interested in learning more about this study, please contact me or complete and return the second page of this letter in the enclosed stamped and addressed envelope. After we receive this information, we will contact you by telephone. Returning this form does not obligate you to join the study.

Thank you for considering participation in this study. We hope that the information learned from this study will benefit others with eye disorders in the future by helping us to better predict, prevent, and treat these conditions. If you have other questions, please contact Linda Reis at (414) 955-7645.

Sincerely,

Linda Reis, MS, CGC Study Coordinator Medical College of Wisconsin Phone: (414) 955-7645 Email: <u>lreis@mcw.edu</u> Please complete this form and return it in the enclosed stamped and addressed envelope if you are interested in participating in this study.

Affected Person's Name(s):
Parents' Names (if affected person is a child):
Street Address:
City, State, Zip:
Home Phone Number:
Work Phone Number:
Please describe your/your child's eye condition below:
Yes, I am interested in participating in Genetic Studies of Human Developmental Disorders. Please contact me.
Please contact me at my:
Home phone
Work phone
Where did you get this letter?
Please return to: Linda Reis/ Elena Semina Medical College of Wisconsin Translational and Biomedical Research Center 8701 Watertown Plank Road Milwaukee, WI 53226