

DIRECTIONS FOR PARTICIPATION IN STUDY

Genetic studies of the congenital cranial dysinnervation disorders: Congenital fibrosis of the extraocular muscles (CFEOM) Congenital ptosis, Duane syndrome, related ocular motility disorders

CHECKLIST:

<input type="checkbox"/>	Participation Form	<input type="checkbox"/>	Yellow top tubes/salivary kits
<input type="checkbox"/>	Physician information sheet	<input type="checkbox"/>	Medical release form
<input type="checkbox"/>	Informed consent	<input type="checkbox"/>	Contacted us re FedEx mailing
<input type="checkbox"/>	Photos / Video (Yes / No)		

Enclosed in this mailing are copies of the Participant information sheet, informed consent(s), a mailing container with the appropriate blood vacutainer tubes or salivary kit, and the pre-addressed Federal Express packaging with our account number in which to return both the blood samples and the paperwork. To enroll in the study:

1. Have each participant fill out the front and back of the Participant information sheet.
2. Have each participant read and sign the Informed Consent form(s), and have a witness co-sign the form.
3. Have the examining physician fill out the physician information sheet, which describes and diagrams the ophthalmologic examination. In addition, please record if the individual has any associated anomalies such as skeletal, limb, muscle, or craniofacial abnormalities, hearing deficits, facial weakness, etc.
4. When possible, please provide photographs and videos of the eye movements of participating individuals.
5. Have 15-20-cc of blood drawn from each individual and aliquoted into the **two** 7-10 cc **yellow top** vacutainers provided. Alternatively if salivary kits were provided please place 2 mls of saliva into kit following the enclosed instructions. Label each tube with the participant's name and birth date. Samples can be stored in the refrigerator (4°C) prior to transport, but do not allow the tubes to freeze.
6. Package all of the paperwork and the blood sample together in the Federal Express diagnostic mailer provided for shipment to us. Place the tubes in the carrying cases and specimen bags. Fill out the date and your return address and telephone number on the FedEx mailing slip, and keep the appropriate copy for your records. Our billing code is pre-typed, so we will be charged for the transport. If there is not a convenient FedEx drop-off box, please call their 800 number for pick-up. Lastly, please contact us at the time of mailing and provide the FedEx number so that we can anticipate the arrival of samples.

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