



Children's Hospital Boston Center for Strabismus Research
Genetic studies of Strabismus, Congenital Cranial Dysinnervation Disorders
(CCDDs) and their associated anomalies



PARTICIPANT CONTACT DETAILS & MEDICAL QUESTIONNAIRE

To be completed by the Research Study Coordinator:

Study Participant ID number: _____ Coordinator initials: _____
 Date Form Completed: MM/DD/YYYY __ / __ / _____

This form should be completed by or on behalf of each participating family member:

Study Participant Demographics

Name: _____ Date of Birth: __ / __ / _____
 Gender: Male Female
 Street Address: _____ Apt/Unit # _____
 City: _____ State: _____ Zip Code: _____ Country: _____
 Home Tel: () _____ Cell Phone: () _____
 Email: _____

Ethnic Background

The National Institute of Health (who are sponsoring our research) require us to collect information on your ethnic background. Would you describe yourself as:

- White, non Hispanic Hispanic Native American or Alaskan Black, non Hispanic
 Asian or Pacific Islander Other

Please describe your ethnic background in detail eg. Mixed European Ancestry: _____

Are you the original study subject, i.e. the person in your family initially identified with the eye disorder? Yes No

If NO, what is your relation to the original study subject?

- Father Mother Sister Brother
 Grandmother Grandfather Uncle Aunt Cousin

Other (please describe): _____



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History of Eye Symptoms/Problems <i>(In the following section, please provide details relating to your ocular health history) :</i>	
What is the name of the eye disorder(s) of the original study subject? _____ (Please see attached key for further details and descriptions of eye conditions we are studying)	
Do you have this eye disorder?	
<input type="checkbox"/> Yes →	Were you born with the eye disorder? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure If NO, how old were you when you were diagnosed? _____ Has the eye condition changed over time? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure If YES, please describe how your eye condition has changed: _____ _____
<input type="checkbox"/> No →	Do you have a different eye disorder? <input type="checkbox"/> Yes _____ <div style="text-align: right;"> <input type="checkbox"/> No <input type="checkbox"/> I'm not sure </div>
<input type="checkbox"/> I'm not sure	
Have you ever seen an ophthalmologist? (eye doctor)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Have you ever had a drooping eyelid (congenital ptosis)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Have you ever had a crossed or wandering eye (amblyopia)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Have you ever had double vision?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you ever tilt your head when looking straight?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Have you ever undergone eye muscle surgery?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Have you ever worn a patch or used eye drops (atropine penalization) for eye correction?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Have you ever worn glasses or contacts?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure

If you answered YES to any of the above questions, please provide further details (i.e. age of onset of eye condition, dates of surgery, name of procedure if known, reason for glasses, etc.)



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Ophthalmologist Information: *If you currently see an ophthalmologist or have seen one in the past, please provide his or her contact information. If your ophthalmologist is at Children's Hospital Boston, you need only provide his/her name.*

Name: _____

Street Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Office Tel: () _____ Fax No: () _____

Email: _____

Other Eye Conditions:	
Do you have a coloboma? (Absence or defect of ocular tissue ranging from a small pit in the optic disk to extensive defects in the iris, ciliary body, choroid, retina, or optic disk),	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have microphthalmia? (Abnormally small eye)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have epibulbar dermoids? (Eye tumors that are not recurrent or progressive)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have any abnormal ocular features? (eg. epicanthal folds-tissue overlapping the nasal corner of the eye, telecanthus- increased distance between the inner corners of the eyes, slanting of the palpebral fissure(s)- openingfor the eyes between the eyelids?)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have any retinal defects? (retinal tears, detachments, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have any visual impairment other than previously noted?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If you answered YES to any question above, please describe: _____	



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Family Ocular History Chart:								
If you are the original study subject, please complete this page by circling as appropriate. See accompanying eye disorder sheet to provide further details. If you are not the main study subject, please continue to Page 5.								
Glasses before age 6	Mother (M)	Father (F)	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Patching	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Amblyopia ("Lazy Eye")	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Common Strabismus	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Eye Muscle Surgery	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Congenital ptosis (Drooping eye since birth)	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Complex Strabismus	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Childhood glaucoma	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Glaucoma	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Childhood cataracts	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Childhood blindness	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Blindness	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Macular Degeneration	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Diabetic Eye Disease	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Other Eye Disease (retinal detachment, etc.)	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Skeletal abnormality	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:



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Family Ocular History Chart continued:								
If you are the original study subject, please complete this page by circling as appropriate. See accompanying eye disorder sheet to provide further details. If you are not the main study subject, please continue to Page 5.								
Organ abnormality	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Neurological Disorder	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Genetic Disorder	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:
Other Disorder	Mother	Father	Brother	Sister	½ sibling through M/F	Grand-Father / Mother	Aunt / Uncle	Other:

If you selected 'Other' please provide further details: _____

Medical History:	
<i>Please provide information regarding your medical history in the following sections. These sections should be completed by, or on behalf of, all participants</i>	
Birth History	
Were you born full term?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If NO, after how many weeks gestations were you born?	_____ weeks
How many pregnancies did your mother have?	_____ pregnancies
Of these pregnancies, how many were live births?	_____ live births
What was your birth weight?	_____ lbs _____ oz <input type="checkbox"/> I'm not sure
How old was your mother when you were born?	_____ years old <input type="checkbox"/> I'm not sure
How old was your father when you were born?	_____ years old <input type="checkbox"/> I'm not sure
Were any medications used during pregnancy?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe when during pregnancy:	
If YES please list all medications taken:	



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Birth History continued	
Did your mother smoke cigarettes during her pregnancy with you?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES, please specify:	<input type="checkbox"/> Until _____ weeks gestation OR <input type="checkbox"/> Throughout pregnancy _____ cigarettes per day
Did your mother drink alcohol during her pregnancy with you?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES, how much?	<input type="checkbox"/> Until _____ weeks gestation OR <input type="checkbox"/> Throughout pregnancy _____ drinks per week
Did your mother have any complications during her pregnancy with you? (eg. placenta previa, gestational diabetes, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Were there any complications during delivery? (i.e. abnormal presentation, c-section, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Did you have a prolonged hospital stay after birth?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Did you fail to thrive in height, weight or head circumference after birth?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	



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General Review	
Which is your dominant hand?	<input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> Ambidextrous <input type="checkbox"/> I'm not sure
What is your current height?	_____ Feet _____ Inches <input type="checkbox"/> I'm not sure
Please describe your current educational experience.	<input type="checkbox"/> Grade School <input type="checkbox"/> Middle School <input type="checkbox"/> High School <input type="checkbox"/> College / University <input type="checkbox"/> Graduate/Professional
If YES please describe:	
Have you ever undergone chromosomal (genetic) analysis?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Have you ever undergone imaging study (eg. CT, MRI)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Have you ever undergone any testing other than already indicated?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Have you ever undergone surgery or been hospitalized?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Please list any medications that you are currently taking.	

Ear / Hearing Function	
Have you had a history of chronic ear infections?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have any hearing loss?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
22a. If YES, please check all that apply:	<input type="checkbox"/> Conductive <input type="checkbox"/> Sensorineural <input type="checkbox"/> Unilateral <input type="checkbox"/> Bilateral <input type="checkbox"/> High frequency <input type="checkbox"/> Low frequency <input type="checkbox"/> Congenital <input type="checkbox"/> Acquired <input type="checkbox"/> Stable <input type="checkbox"/> Fluctuating
Do you have any ear abnormalities including low set ears, abnormal lobe shape, or pre-auricular appendages?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	

Children's Hospital Boston, CLS14076, 3 Blackfan Circle, Boston, MA 02115

Tel: 617-919-2168/617-919-2164



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Developmental History	
Do you have/have you ever had any developmental delays?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES, please check all that apply:	<input type="checkbox"/> Gross Motor <input type="checkbox"/> Speech and Language <input type="checkbox"/> Fine Motor <input type="checkbox"/> Social
Do you have/have you ever had any learning disabilities?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Do you have Attention Deficit (Hyperactivity) Disorder?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Do you have Autism Spectrum Disorder?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	

Neurological Function	
Have you ever been diagnosed with depression, a mood disorder or other psychiatric disease?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES please describe:	
Do you have a history of seizures?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had altered facial sensation?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had facial weakness?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had problems swallowing?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had problems tasting?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had a Peripheral Neuropathy (a condition of the nervous system that usually causes tingling, burning and/or weakness in the face, hands, arms, legs and/or torso)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES, is it:	<input type="checkbox"/> Axonal <input type="checkbox"/> Myelinating <input type="checkbox"/> I'm not sure
Do you have/have you ever had any muscle weakness?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure



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Neurological Function continued	
If YES, is it:	<input type="checkbox"/> Progressive <input type="checkbox"/> Static <input type="checkbox"/> Improving <input type="checkbox"/> I'm not sure
Do you have/have you ever had abnormal muscle tone?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If YES, is it:	<input type="checkbox"/> Low <input type="checkbox"/> High <input type="checkbox"/> I'm not sure
Do you have/have you ever had episodes of ataxia (clumsy and unsteady movement of the limbs)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any other neurological issues? If you answered YES above, please describe in more detail:	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure

Heart, Lung and Gastrointestinal Function	
Do you have/have you ever had any congenital (since birth) heart defects?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any other cardiac problems?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any allergies/asthma?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any other respiratory problems	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any gastrointestinal problems? (eg. Gastroesophageal Reflux Disease (GERD), irritable bowel syndrome, Celiac Disease, constipation, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If you answered YES to heart, lung and gastrointestinal function, please describe in more detail:	

Urinary/Genital Function	
Do you have/have you ever had any problems or birth anomalies related to your kidneys (eg. ectopic kidney—a kidney not located in its normal place, multicystic dysplastic kidney-development of cysts in the kidney, hydronephrosis-abnormal kidney enlargement)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any genitalia or reproductive organ problems or birth anomalies?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure

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If you answered YES above, please describe in more detail:

Musculoskeletal & Ectodermal (Skin) Function	
Do you have fused vertebrae?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have Scoliosis?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have Arthrogryposis (stiff joints and abnormal muscle development)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any upper limb defects (eg. arm, hand, finger)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any lower limb defects (eg. leg, foot, toes)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
Do you have/have you ever had any problems or birth anomalies related to your skin, hair, teeth, or nails? (i.e. eczema, soft teeth, missing nails, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure
If you answered YES above, please describe in more detail:	

Is there any other information related to your medical history or family history you feel would be helpful for this study?

Thank you for completing our questionnaire!