

Research Team Use Only

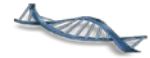
Study Participant ID number: _____

Form Received: MM/DD/YYYY _____ / _____ / _____

INDEX-WITH DIAGNOSIS

By (Lab team member last name): _____

Genetic Studies of Strabismus, Congenital Cranial Dysinnervation Disorders (CCDDs) and Associated Anomalies: Engle Lab



Today's Date: MM/DD/YYYY _____ / _____ / _____

Participant Demographics (this is the person affected by the condition)

Name: _____ Date of Birth MM/DD/YYYY _____ / _____ / _____
First Last

Gender (circle): Male Female Current Age: _____

Phone #s: Home _____ Cell _____ Work _____
Please circle preferred number

Mailing Address: _____
Street City State Zip

Email Address: _____

Name and Contact Information for **Person Completing Form** *Please circle here if completing for yourself* → SELF

Full Name: _____ Relationship to Participant: _____

Race, Ethnicity & Family Background

The National Institutes of Health (NIH) provides federal funding for this research and requires that the following information be collected and self-reported by participants. Please answer both ethnicity and race questions below:

Ethnicity: Hispanic/Latino Not Hispanic/Latino

Race: American Indian or Alaska Native Asian Black or African American
 Native Hawaiian or Other Pacific Islander White Multiracial/Mixed/Other

Please detail countries of origin/ancestry for your families (ex: Nigerian, Ashkenazi, Mixed European, Mexican).

Mother's Family: _____

Father's Family: _____

Are the parents of the person listed on the first line/your parents related by blood, such as first or second cousins?

NO YES → If yes, please detail: _____

Are you the person in the family initially diagnosed with the eye disorder?

YES NO → If NO, please note below **your** biological relationship to the original study subject:

I am the person's:

MOTHER FATHER SISTER FULL HALF BROTHER FULL HALF

MATERNAL AUNT UNCLE COUSIN GRANDMOTHER GRANDFATHER

PATERNAL AUNT UNCLE COUSIN GRANDMOTHER GRANDFATHER

Eye Symptoms/Problems (In the following section, please provide details relating to your ocular health history)	
Have you ever had or suspected strabismus (misaligned eyes)?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
What condition(s) do you currently have? Please indicate *all* conditions that apply.	<input type="checkbox"/> Esotropia (crossed/ inward drifting/deviated eye) <input type="checkbox"/> Exotropia (wandering or outward drifting/deviated eye) <input type="checkbox"/> Hyper or hypotropia (vertical deviation, eye drifts up or down) <input type="checkbox"/> Other forms or unsure (specify if known): _____ <input type="checkbox"/> Prior strabismus, condition resolved at age _____
Has this condition been diagnosed by a specialist?	<input type="checkbox"/> Yes at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
If yes, have you had eye muscle surgery to correct strabismus?	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
If you have had eye surgery, or if your strabismus has changed, what direction did your eye(s) originally deviate?	<input type="checkbox"/> Esotropia <input type="checkbox"/> Exotropia <input type="checkbox"/> Hyper or hypotropia <input type="checkbox"/> Other forms or unsure (specify below if known):
Do you have amblyopia (decreased vision in one eye or "lazy eye")?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Have you ever been treated for amblyopia (patching an eye or using atropine eye drops)?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Did you wear glasses before age 6?	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you wear glasses now?	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
If Yes→Why do you wear glasses? Please indicate all that apply and note here if for a different reason than those provided:	<input type="checkbox"/> Myopia (or nearsighted) <input type="checkbox"/> Hyperopia (or farsighted) <input type="checkbox"/> Anisometropia (unequal focusing of the eyes) <input type="checkbox"/> Astigmatism <input type="checkbox"/> Presbyopia (reading glasses needed as an adult)
Do you have reduced or absent stereopsis (trouble with depth perception)?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Can you appreciate 3D movies, games pictures etc?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have double vision?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have ptosis (droopy eyelid)?	<input type="checkbox"/> Yes→ <input type="checkbox"/> Both Eyes <input type="checkbox"/> Left Eye Only <input type="checkbox"/> Right Eye Only <input type="checkbox"/> No <input type="checkbox"/> Not sure
Any other eye condition not mentioned above?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure Please detail:
As an infant, when did you first produce tears?	<input type="checkbox"/> Unknown/ No Concerns Noted At age:
Do you tear when eating or chewing?	<input type="checkbox"/> Yes, started at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have dry eyes?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
If your eyes are dry, what treatment do you use?	

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"/> Both Eyes <input type="checkbox"/> Left Eye Only <input type="checkbox"/> Right Eye Only <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have microphthalmia? ~unusually small eye(s).	<input type="checkbox"/> Yes → <input type="checkbox"/> Both Eyes <input type="checkbox"/> Left Eye Only <input type="checkbox"/> Right Eye Only <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have epibulbar dermoids? ~Eye tumors that are not recurrent or progressive.	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have any other unusual ocular features/conditions? (examples: 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)-opening for the eyes between the eyelids?).	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes → Condition Details:
Do you have any retinal defects? (retinal tears, detachments, etc.).	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
If you answered YES to any question above, please describe:	

Family Ocular History Chart								
If you are the original study subject , please complete this section by circling and marking boxes as appropriate.								
Glasses before age 6	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Patching	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Amblyopia ("Lazy Eye")	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Common Strabismus	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Eye Muscle Surgery	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Congenital ptosis (Drooping eye since birth)	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Complex Strabismus	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Childhood glaucoma	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal

Glaucoma	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Childhood cataracts	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Childhood blindness	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Blindness	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Macular Degeneration	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Diabetic Eye Disease	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Other Eye Condition (retinal detachment, etc.)	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Skeletal abnormality	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Organ abnormality	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Neurological Disorder	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Genetic Disorder	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal
Other Disorder	Mother	Father	Brother <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Sister <input type="checkbox"/> Full <input type="checkbox"/> Half maternal <input type="checkbox"/> Half paternal	Grandmother <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Grandfather <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Aunt <input type="checkbox"/> maternal <input type="checkbox"/> paternal	Uncle <input type="checkbox"/> maternal <input type="checkbox"/> paternal

If any other relatives, such as cousins, have been diagnosed with, or you marked **any** relatives as affected by, any of these conditions, please provide further details: _____

Medical History:

Please provide information regarding your medical history in the following sections. These sections should be completed by, or on behalf of, all participants

Birth History

Were you born prematurely? Yes No Not sure
If Yes→How far along was your mother when you were born? _____ weeks

How many pregnancies did your mother have? _____ pregnancies

Of these pregnancies, what was the outcome?	_____ live births _____ pregnancy losses
What was your birth weight?	_____ lbs _____ oz <input type="checkbox"/> Not sure
What was your birth length?	_____ inches <input type="checkbox"/> Not sure
How old was your mother when you were born?	_____ years old <input type="checkbox"/> Not sure
How old was your father when you were born?	_____ years old <input type="checkbox"/> Not sure
Were any medications used during pregnancy?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please describe what medications and when they were taken:
Did your mother smoke cigarettes during her pregnancy with you?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share if <input type="checkbox"/> She continued throughout pregnancy <input type="checkbox"/> She stopped at _____ weeks She had _____ cigarettes per day
Did your mother drink alcohol during her pregnancy with you?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share if <input type="checkbox"/> She continued throughout pregnancy <input type="checkbox"/> She stopped at _____ weeks She had _____ drinks per week
Were there any complications during the pregnancy? (eg. placenta previa, gestational diabetes, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Were there any complications during delivery? (i.e. abnormal presentation, c-section, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Was there a prolonged hospital stay after birth?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Were there concerns with failure to thrive or problems related to size, height, weight or head circumference after birth?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:

General Review	
Which is your dominant hand?	<input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> Ambidextrous <input type="checkbox"/> Not sure
What is your current height?	_____ Feet _____ Inches <input type="checkbox"/> Not sure

What is your current weight?	_____ pounds/kg
Please describe your highest educational experience.	<input type="checkbox"/> Elementary <input type="checkbox"/> Middle School <input type="checkbox"/> High School <input type="checkbox"/> College/University <input type="checkbox"/> Graduate/Professional
Have you ever undergone any genetic testing?	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you ever undergone imaging study (eg. CT, MRI)	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you ever undergone any testing other than already indicated?	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you ever undergone surgery or been hospitalized?	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Please list any prescription or over the counter medications you are currently taking and reason.	

Ear / Hearing Function	
Have you had a history of chronic ear infections?	<input type="checkbox"/> Yes, at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Do you have any hearing loss?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If YES→Please check all that apply and note details (age of onset, if one ear or both are affected) below
<u>HEARING LOSS DETAILS</u>	
<input type="checkbox"/> Conductive at age _____ <input type="checkbox"/> Bilateral <input type="checkbox"/> Unilateral R or L <input type="checkbox"/> High frequency at age _____ <input type="checkbox"/> Bilateral <input type="checkbox"/> Unilateral R or L <input type="checkbox"/> Stable <input type="checkbox"/> Progressive <input type="checkbox"/> Fluctuating	<input type="checkbox"/> Sensorineural at age _____ <input type="checkbox"/> Bilateral <input type="checkbox"/> Unilateral R or L <input type="checkbox"/> Low frequency <input type="checkbox"/> Bilateral <input type="checkbox"/> Unilateral R or L <input type="checkbox"/> Congenital/since birth <input type="checkbox"/> Acquired due to: <input type="checkbox"/> Age <input type="checkbox"/> Exposure Details: <input type="checkbox"/> Accident Details:

Do you have any unusual ear features including low set ears, unusual lobe shape, or pre-auricular appendages?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
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Developmental History	
Do you have/have you ever had any developmental delays?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
	<input type="checkbox"/> Gross Motor <input type="checkbox"/> Speech and Language <input type="checkbox"/> Fine Motor <input type="checkbox"/> Social
Have you been diagnosed with any learning disabilities?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you been diagnosed with Attention Deficit (Hyperactivity) Disorder (ADD/ADHD)?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you been diagnosed with Autism Spectrum Disorder?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:

Neurological Symptoms	
Do you have, or have you ever suffered from anxiety? (generalized anxiety, social phobia, panic disorder, agoraphobia, obsessive-compulsive disorder, specific phobia, post-traumatic stress disorder)	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you ever been diagnosed with depression, a mood disorder, or other psychiatric disease?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you ever had a seizure or epilepsy?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Any current or past altered facial sensation?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Do you have/have you ever had facial weakness?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:

Do you have/have you ever had problems swallowing?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details:	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Do you have/have you ever had problems tasting?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details:	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Do you have a normal sense of smell?	<input type="checkbox"/> Yes sure	<input type="checkbox"/> No	<input type="checkbox"/> Not sure If NO→Please share details:
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, diagnosed at age If Yes→Please share details: <input type="checkbox"/> Axonal <input type="checkbox"/> Myelinating	<input type="checkbox"/> No	<input type="checkbox"/> Not sure <input type="checkbox"/> Not sure
Do you have/have you ever had any muscle weakness?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details: What part of body:_____	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Do you have/have you ever had abnormal muscle tone?	<input type="checkbox"/> Progressive <input type="checkbox"/> Stable <input type="checkbox"/> Improving	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Do you have/have you ever had abnormal muscle tone?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details: <input type="checkbox"/> Low Tone <input type="checkbox"/> High Tone	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Do you have/have you ever had episodes of ataxia (clumsy and unsteady movement of the limbs)?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details:	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Do you have/have you ever had any other neurological issues?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details:	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
If you answered YES above, please describe in more detail if you need more room:			

Endocrine and hypothalamic function

Do you have short stature or specific growth abnormalities?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details:	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Have you entered puberty?	<input type="checkbox"/> Yes, at age	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Have you developed body hair and bodily odor?	<input type="checkbox"/> Yes, at age	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
If you are female and have entered puberty, at what age did your periods first start?	<input type="checkbox"/> Yes, at age	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
If you are male, were there any concerns during your infancy of small penis or undescended testicles?	<input type="checkbox"/> Yes, diagnosed at age	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
Do you have any sleep problems?	<input type="checkbox"/> Yes, diagnosed at age If Yes→Please share details:	<input type="checkbox"/> No	<input type="checkbox"/> Not sure

Do you have difficulty with controlling your appetite or having low desire to eat?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Have you unintentionally gained or lost significant weight in the last year? (10 or more pounds)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details: <input type="checkbox"/> Gained _____pounds <input type="checkbox"/> Lost _____pounds
Do you have, or have you ever, had any difficulty regulating your body temperature?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:

Heart, Lung and Gastrointestinal Function	
Do you have/have you ever had any heart defects?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have/have you ever had any other cardiac problems?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have/have you ever had any allergies/asthma?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have/have you ever had any other respiratory problems?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have/have you ever had any gastrointestinal problems?(eg. Gastroesophageal Reflux Disease (GERD), irritable bowel syndrome, Celiac Disease, severe/recurrent constipation.)	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure
Problems with abnormal or excessive vomiting?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure
Have you ever been hospitalized for vomiting?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> 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, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure If Yes→Please share details:
Do you have/have you ever had any genitalia or reproductive organ problems or birth anomalies?	<input type="checkbox"/> Yes, diagnosed at age _____ <input type="checkbox"/> No <input type="checkbox"/> Not sure
If you answered YES above, please describe in more detail:	

Musculoskeletal & Ectodermal (Skin) Function	
Do you have fused vertebrae?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have scoliosis?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have arthrogryposis? ~stiff joints and abnormal muscle development	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have/have you ever had any upper limb defects (eg. arm, hand, finger)?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> Not sure
Do you have/have you ever had any lower limb defects (eg. leg, foot, toes)?	<input type="checkbox"/> Yes, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> 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, diagnosed at age <input type="checkbox"/> No <input type="checkbox"/> 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 us to know?

Physician Information: <i>If you currently see an ophthalmologist or other specialist, or have seen one in the past, please provide his or her contact information. If your physician is at Boston Children's Hospital, you need only provide his/her name.</i>	
Did your ophthalmologist refer you to this study? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure	
Ophthalmologist Name: _____	
Hospital Affiliation: _____	Phone _____ Fax _____
Mailing Address: _____	
Street	City State Zip
Email Address: _____	

If someone other than your ophthalmologist referred you to the study, please note that person here:

Other Specialist Name: _____ Specialty _____

Hospital Affiliation: _____ Phone _____ Fax _____

Mailing Address: _____
Street City State Zip

Email Address: _____

***Thank you for completing our questionnaire and for your important
contribution to this research!***