



Children's Hospital Boston Center for Strabismus Research
Genetic studies of strabismus, congenital cranial dysinnervation disorders
(CCDDs) and their associated anomalies



OPHTHALMOLOGICAL DATA COLLECTION FORM

This form should be completed by the study participant's examining physician:

Examining Physician Contact Details

Participant Background Information

Visual Acuity & Refraction Status

Anomalous Head Posture

Lid Position

Ocular Alignment (Strabismus)

Ocular Motility

Additional documentation request

Associated Findings

Our Contact Details



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1. Examining physician contact details:

Name of examiner: Title: _____ First name: _____ Last name: _____

Department and Street Address: _____

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

Tel: () _____ Email: _____

2. Study participant background details:

Name of participant: _____ Date of Birth: __ / __ / ____

Collaborating Institution's patient code: _____ Date of patient examination: __ / __ / ____

Is the participant affected by the eye disorder? Yes No

Is the participant affected by associated anomalies Yes No

Preliminary Diagnosis:

Congenital Ptosis Duane syndrome

HOXA1-related syndromes Horizontal Gaze Palsy with Progressive Scoliosis (HGPPS)

Congenital Fibrosis of Extraocular Muscles (CFEOM) Marcus Gunn syndrome Moebius syndrome

Other (please describe) _____

Neuro-imaging undertaken? Yes No

Findings: _____

Copy can be provided

Describe family's concerns: e.g. poor vision, abnormal head position, drooping lids etc:

Has the participant undergone previous ocular (including eyelid) surgery? Yes No

Please describe in brief (list details on separate sheet if necessary):

Surgical date(s): _____

Details of the surgery: _____

Is surgical pathology tissue available? Yes No Details of tissue: _____



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3. Visual acuity, refraction & general ocular examination:

Age at 1 st exam ___ yrs ___ mths	Age at last exam ___ yrs ___ mths	Date of last exam: __ / __ / ____
Does patient require optical correction? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Cycloplegic refraction: OD: _____ OS: _____	Prescription given: OD: _____ OS: _____	
Does the participant use the optical correction (if prescribed)? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not regularly		
Best corrected visual acuity:	OD: _____ OS: _____ OU: _____	Method: <input type="checkbox"/> Snellen <input type="checkbox"/> HOTV <input type="checkbox"/> Pictures <input type="checkbox"/> PLT <input type="checkbox"/> Fixation pattern
Pupil assessment:	Size / Shape: Reaction to light / near:	
Anterior segment examination	<input type="checkbox"/> Normal <input type="checkbox"/> Findings (provide details)	
Fundus examination:	<input type="checkbox"/> Normal <input type="checkbox"/> Findings (provide details)	



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4. Head posture:

Is an Anomalous Head Position (AHP) present? <input type="checkbox"/> Yes <input type="checkbox"/> No		
If yes, please describe:		
Head Turn:	<input type="checkbox"/> Right <input type="checkbox"/> Left <input type="checkbox"/> None	<input type="checkbox"/> Small (5-10°) <input type="checkbox"/> Moderate (10-19°) <input type="checkbox"/> Marked (>20°)
Chin Position	<input type="checkbox"/> Chin up <input type="checkbox"/> Chin down <input type="checkbox"/> None	<input type="checkbox"/> Small (5-10°) <input type="checkbox"/> Moderate (10-19°) <input type="checkbox"/> Marked (>20°)
Head Tilt	<input type="checkbox"/> Tilts to Right Shoulder <input type="checkbox"/> Tilts to Left Shoulder <input type="checkbox"/> None	<input type="checkbox"/> Small (5-10°) <input type="checkbox"/> Moderate (10-19°) <input type="checkbox"/> Marked (>20°)
Is the head posture to allow fixation with one eye? Both eyes (i.e. fusion)? _____		

5. Ptosis measurements:

Is ptosis present?	<input type="checkbox"/> No	<input type="checkbox"/> Yes right eye	<input type="checkbox"/> Yes left eye
	Right eye	Left eye	
Interpalpebral fissure (range 0-15mm)	_____	_____	
Marginal reflex distance (range 0-10mm)	_____	_____	
Levator without frontalis (range 0-20mm)	_____	_____	



6. Ocular alignment:

Primary position alignment:
 (i.e. head held in straight ahead position) _____

Alignment with AHP: _____

Other positions (if possible):

<p>Example 1:</p> <table style="width: 100%;"> <tr> <td style="text-align: center;">Right eye</td> <td style="text-align: center;">Left eye</td> </tr> <tr> <td style="text-align: center;"></td> <td style="text-align: center;"></td> </tr> </table> <p align="center">Both eyes are down and out. Neither eye can fixate in primary position.</p>	Right eye	Left eye			<p>Example 2:</p> <table style="width: 100%;"> <tr> <td style="text-align: center;">Right eye</td> <td style="text-align: center;">Left eye</td> </tr> <tr> <td style="text-align: center;"></td> <td style="text-align: center;"></td> </tr> </table> <p align="center">Right is fixating in primary position. Left eye is esotropic</p>	Right eye	Left eye		
Right eye	Left eye								
Right eye	Left eye								

Check appropriate boxes to describe resting position and place black dot to indicate position of each eye with head straight ahead:

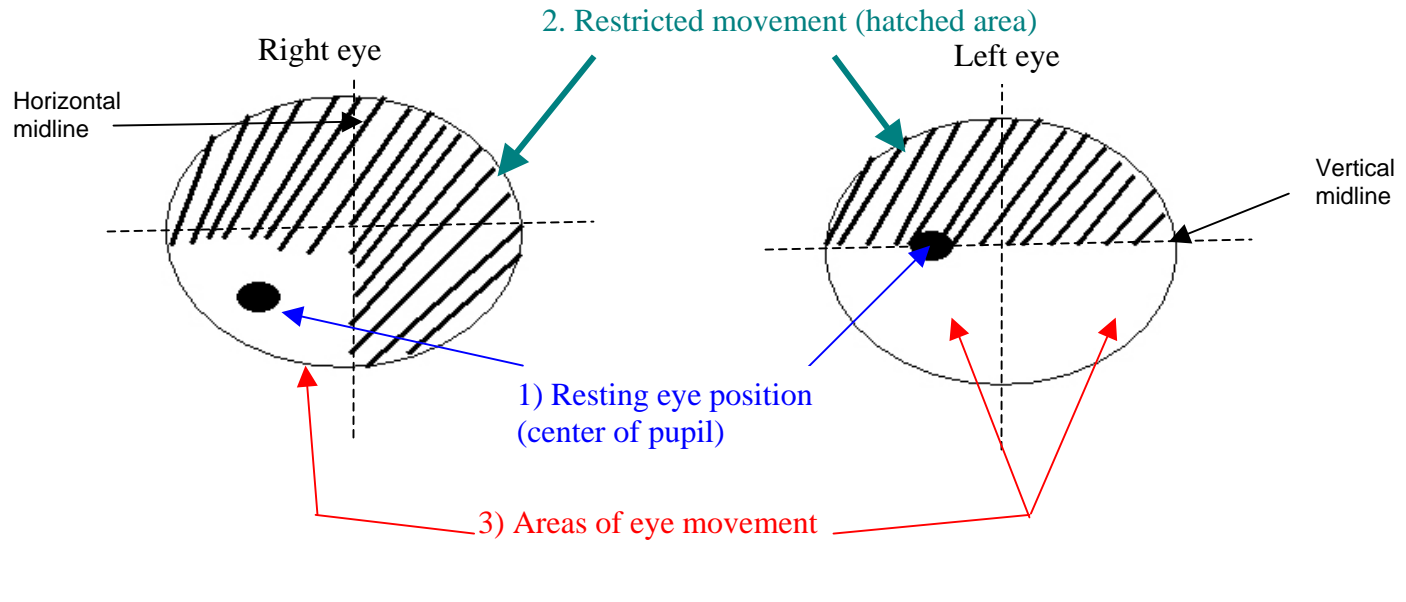
<p>Right eye</p> <input type="checkbox"/> Straight ahead position <input type="checkbox"/> Exotropic position <input type="checkbox"/> Esotropic position <input type="checkbox"/> Hypertropic position (supraducted) <input type="checkbox"/> Hypotropic position (infraducted)	<p>Right eye</p>	<p>Left eye</p>	<p>Left eye</p> <input type="checkbox"/> Straight ahead position <input type="checkbox"/> Exotropic position <input type="checkbox"/> Esotropic position <input type="checkbox"/> Hypertropic position (supraducted) <input type="checkbox"/> Hypotropic position (infraducted)
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7. Ocular motility instruction page:

Please comment on the degree of movement of each eye. Scoring as a percent (%) of normal range or using a +/- system may be difficult given the anchored position of the eye(s). One suggestion is to label directions of limited or absent movement by "crossing out" it out.

Example: Neither eye in this case can reach primary position. Both eyes begin their movement from a non-straight ahead position.



Explanation:

Right eye:

1. Resting globe position (black dot) = slightly infraducted & abducted
2. No elevation. Unable to reach vertical midline.
3. Full depression from infraducted starting position
4. Adducts only to horizontal midline but not beyond.
5. Abducts fully from starting abducted position

Left eye:

1. Resting globe position (black dot) = at vertical midline but slightly adducted
2. No elevation above vertical midline
3. Full depression in both abduction & adduction
4. Full horizontal eye movements



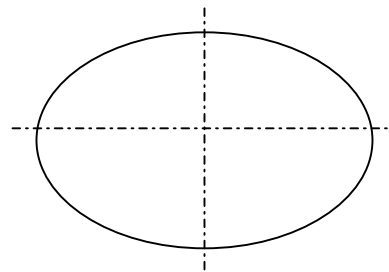
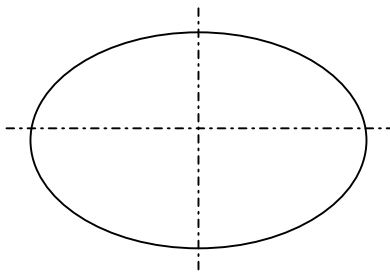
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Please feel free to write comments in addition to diagramming extent of eye movement limitations.

Right eye

Left eye



Please comment on the following:	Observations
Globe retraction: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Aberrant movement (i.e. synergistic divergence or synergistic convergence) <input type="checkbox"/> Yes <input type="checkbox"/> No	
Nystagmus: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Quality of eye movement i.e. smooth, jerky <input type="checkbox"/> Yes <input type="checkbox"/> No	
Bell's phenomenon: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Was forced duction testing undertaken? <input type="checkbox"/> Yes <input type="checkbox"/> No	



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8. Additional documentation:

The following would be very useful in further defining this participant's phenotype. Please check box if sending this information.

- a) Photo of any preferred head position (abnormal head position)
- b) Photo with head held in straight ahead position with lids not held
- c) Photo with head held in straight ahead position with lids held open (if ptosis present)
- d) Video or still images of ocular motility – horizontal and vertical versions and ductions

9. Other Associated features

- | | |
|--|---|
| <input type="checkbox"/> Other cranial nerve abnormalities: <ul style="list-style-type: none"><input type="checkbox"/> Hearing<input type="checkbox"/> Facial weakness or facial sensation abnormality<input type="checkbox"/> Tearing abnormality<input type="checkbox"/> Swallowing abnormality<input type="checkbox"/> Oral dysfunction/tongue abnormality<input type="checkbox"/> Respiratory problems<input type="checkbox"/> Other | <input type="checkbox"/> Craniofacial malformation |
| <input type="checkbox"/> Intellectual development delay/mental retardation/autism | <input type="checkbox"/> Spine |
| <input type="checkbox"/> Motor development delay/hypotonia/dyscoordination | <input type="checkbox"/> Extremity malformation |
| <input type="checkbox"/> Ataxia | <input type="checkbox"/> Other malformations (Poland, Klippel Feil) |
| <input type="checkbox"/> Other neurological | <input type="checkbox"/> Organ anomalies |
| <input type="checkbox"/> Other associated features | <input type="checkbox"/> Skin |
| | <input type="checkbox"/> Heart |
| | <input type="checkbox"/> Lungs |
| | <input type="checkbox"/> Kidney |
| | <input type="checkbox"/> GI |
| | <input type="checkbox"/> Other |

If any items were checked, please attach further details on accompanying pages.

10. Please send materials and direct questions to:

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