

Dystonia Clinical Data Elements

Principal Investigator Responsible for Accuracy of Data (Name): _____ **Subject ID Number:** _____

Is this data Longitudinal (Follow-Up) Data? Yes No

Collected Family: Yes No If Yes, list subject ID/s: _____

Age: _____ **Gender:** Male Female

Ethnic Category (as reported by subject)-Check one: Hispanic or Latino Not Hispanic or Latino

Racial Categories (as reported by subject) Check One:

American Indian Asian Other Pacific Islander African American Caucasian Other Unknown

Additional Racial and Ethnicity Information: _____

Country of Residence _____

Affected Status: Yes No At Risk

Age At Diagnosis: _____ **Age at Onset:** _____ **YOB:** _____ **Last Known Alive Date:** _____

Diagnosed By: Neurosurgeon Neurologist Pediatric Neurologist Pediatrician Primary Care Physician
 Psychiatrist Psychologist Does Not Apply (Population or Family-Based Control) Other

Data Collected By: Neurosurgeon Neurologist Pediatric Neurologist Primary Care Physician Pediatrician
 Psychiatrist Psychologist Research Coordinator Registered Nurse Research Coordinator/ RN Other

Subject Zip Code (1st 3 digits): _____

Medical History

Primary Dystonia Type:

Focal Hemi Generalized Multi-focal Segmental

Hemi Dystonia:

Left Right

Focal Dystonia:

Laryngeal - Abductor Laryngeal - Adductor Laryngeal - Mixed
 Limb - Upper extremity Limb - Lower extremity Cervical
 Cranial - Blepharospasm only Cranial - Oromandibular Cranial - Lingual Cranial - Upper and lower facial movements

Segmental Dystonia:

Cranial-Cervical Cranial-Laryngeal Cranial-Laryngeal-Cervical Cervical-Limb
 Laryngeal-Limb Cervical-Laryngeal Laryngeal-Cervical-Limb Both upper extremities

Other Dystonia Syndrome: Yes No

Please specify: _____

Non-dystonia Syndrome: Yes No

Please specify: _____

Documented Causal Gene: Yes No Unknown

Documented Gene:

DYT1_G DYT1_A DYT3 DYT5A_DYT14 DYT5B DYT6
 DYT8 DYT11 DYT12 DYT16 DYT18 Other Gene

Other Gene: _____

Initial Areas of Onset:

- Foot Left Right
- Hand Left Right
- Jaw
- Larynx
- Lower Face Left Right
- Neck
- Pelvis
- Shoulder Left Right
- Tongue
- Trunk
- Upper Arm Left Right
- Upper Face Left Right
- Upper Leg Left Right

Onset Task Specific: Yes No

Tasks:

- Sports Related Cramp Writers Cramp Typists Cramp Musicians Cramp Speech related dystonia (spasmodic dysphonia)

Other Cramp: _____

Notes: _____

Other Tasks: _____

Dystonia had abrupt onset (less than 1 week): Yes No Unknown

Dystonia was fixed at onset: Yes No Unknown

Psychiatric disorder present: Yes No

Type of psychiatric disorder:

Depression Anxiety related disorders

Other psychiatric conditions: _____

Examination

- Abductor: Yes No
- Adductor: Yes No
- Muscular Tension Dysphonia: Yes No
- Atypical Dysphonia: Yes No
- Laryngeal Tremor: Yes No
- Confirmed by Nasopharyngeoscopy: Yes No
- Tremor preceded dystonia at onset: Yes No
- Myoclonus: Yes No
- Parkinsonism: Yes No

Sites Currently Affected:

<input type="checkbox"/> Foot	<input type="checkbox"/> Left	<input type="checkbox"/> Right	<input type="checkbox"/> Foot Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Hand	<input type="checkbox"/> Left	<input type="checkbox"/> Right	<input type="checkbox"/> Hand Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Jaw			<input type="checkbox"/> Jaw Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Larynx						
<input type="checkbox"/> Neck			<input type="checkbox"/> Neck Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Pelvis			<input type="checkbox"/> Pelvis Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Shoulder	<input type="checkbox"/> Left	<input type="checkbox"/> Right	<input type="checkbox"/> Shoulder Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Tongue			<input type="checkbox"/> Tongue Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Trunk			<input type="checkbox"/> Trunk Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Upper Arm	<input type="checkbox"/> Left	<input type="checkbox"/> Right	<input type="checkbox"/> Upper Arm Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Upper Face	<input type="checkbox"/> Left	<input type="checkbox"/> Right	<input type="checkbox"/> Upper Face Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky
<input type="checkbox"/> Upper Leg	<input type="checkbox"/> Left	<input type="checkbox"/> Right	<input type="checkbox"/> Upper Leg Tremor	Tremor Type:	<input type="checkbox"/> Regular	<input type="checkbox"/> Irregular/Jerky

Family History:

Family history of dystonia: Yes No Unknown

Father affected: Yes No Unknown

Mother affected: Yes No Unknown

Sisters unknown: _____

Sisters unaffected: _____

Sisters affected: _____

Brothers unknown: _____

Brothers unaffected: _____

Brothers affected: _____

Daughters unknown: _____

Daughters unaffected: _____

Daughters affected: _____

Sons unknown: _____

Sons unaffected: _____

Sons affected: _____

Documented Causal Gene: Yes No Unknown

Documented Gene:

<input type="checkbox"/> DYT1_G	<input type="checkbox"/> DYT1_A	<input type="checkbox"/> DYT3	<input type="checkbox"/> DYT5A_DYT14	<input type="checkbox"/> DYT5B	<input type="checkbox"/> DYT6
<input type="checkbox"/> DYT8	<input type="checkbox"/> DYT11	<input type="checkbox"/> DYT12	<input type="checkbox"/> DYT16	<input type="checkbox"/> DYT18	<input type="checkbox"/> Other Gene

Other Gene: _____

Family Member(s) with Tremor present: Yes No Unknown

Family Member(s) with Myoclonus present: Yes No Unknown

Family Member(s) with Parkinson disease or Parkinsonism: Yes No Unknown

Family Member(s) with Other disorders: Yes No Unknown

Other disorders (if yes, please specify): _____