CEREBRAL PALSY RESEARCH REGISTRY Questionnaire

ID Number (to be filled in by coordinator) _____

Please fill out this form to the best of your ability. Mark boxes with a check ☑ or ☒ to indicate your choices.

REGISTRANT CONTACT INFORMATION			
First name:	**Middle name:**		**Last name:**
Guardian 1 First name: Last name:		Relationship:	☐ mother ☐ father ☐ legal guardian ☐ other _____
Guardian 2 First name: Last name:		Relationship:	☐ mother ☐ father ☐ legal guardian ☐ other _____
Street address: Line 1 Line 2			
City:		**State:**	**Zip code:**
Email address:			
Alternative email: *We collect this in case you stop using your primary address. (optional)*			
Phone number:		Phone type:	☐ home ☐ work ☐ cell
Name and email address or phone number of a person we can contact if we cannot reach you over a prolonged period of time:			
Are you willing to be contacted about research studies?		☐ Yes ☐ No	

REGISTRANT DEMOGRAPHIC INFORMATION Please answer the following questions as it relates to the person with cerebral palsy.	
Sex:	☐ male ☐ female
Ethnicity:	☐ Not Hispanic or Latino ☐ Hispanic or Latino ☐ Unknown ☐ Do not wish to report

REGISTRANT DEMOGRAPHIC INFORMATION (Continued)

Race:	☐ White/Caucasian ☐ Hispanic ☐ Middle Eastern ☐ Black/African American ☐ American Indian ☐ Asian ☐ Other (including mixed) ☐ Unknown ☐ Do not wish to report
Biological mother's date of birth:	
Biological mother's highest level of education?	☐ Did not finish high school ☐ High School or GED ☐ Some college/no degree ☐ Associate's degree ☐ Bachelor's degree ☐ Master's degree ☐ Doctoral degree
Primary language spoken at home:	☐ English ☐ Spanish ☐ Polish ☐ Other: _____
Are the parents/guardians fluent in English?	☐ fluent in English ☐ requires interpreter
Is the registrant fluent in English?	☐ fluent in English ☐ requires interpreter

REGISTRANT BIRTH HISTORY	
Date of birth:	
Hospital of birth:	
Place of birth (country):	If USA, what state?
Birth weight: *How much did the registrant weigh when they were born?*	_____ pounds and _____ ounces **OR** ☐ I'm not sure the exact weight ☐ Unknown ☐ 8 pounds 13 ounces or greater (high birth weight) ☐ 5 pounds 8 ounces to 8 pounds 12 ounces (Normal birth weight) ☐ 3 pounds 4.91 ounces to 5 pounds 7 ounces (Low birth weight) ☐ 2 pounds 3.2 ounces to 3 pounds 4.90 ounces (Very low birth weigh) ☐ less than 3 pounds 4.9 oz (Extremely low birth weight)

REGISTRANT BIRTH HISTORY (Continued)

Gestational age:

How many weeks pregnant was the mother when the registrant was born?

_____ weeks and _____ days **OR** ☐ I'm not sure the exact age

☐ Unknown
☐ greater than 41 weeks (Post term)
☐ 37-41 weeks (Full term)
☐ 32-36 weeks (Moderately preterm)
☐ 28-31 weeks (Very preterm)
☐ 21-27 weeks (Extremely preterm)

Did the registrant spend time in the Neonatal Intensive Care Unit (NICU)?

☐ Yes How many days? _____
☐ No

Was it a multiple birth?

☐ No
☐ Yes birth order _____ of
☐ twins
☐ triplets
☐ 4
☐ 5
☐ 6
☐ >6

Was there assistance with conception?

☐ No
☐ Yes What type?
☐ fertility drugs
☐ ovulation stimulation
☐ artificial insemination
☐ intra-cytoplasmic sperm injection (ICSI)
☐ in-vitro fertilization (IVF)
☐ gamete intra-fallopian transfer (GIFT)
☐ unknown
☐ other: _____

Number of previous live births to the biological mother:

Number of previous stillbirths (>20 weeks gestation) to biological mother:

Number of previous miscarriages (<20 weeks gestation) to biological mother:

REGISTRANT CEREBRAL PALSY HISTORY

Limbs affected:

Select the description that best matches the type of cerebral palsy that the registrant has been diagnosed with.

- ☐ one extremity (monoplegia)
- ☐ left arm and left leg (left hemiplegia)
- ☐ right arm and right leg (right hemiplegia)
- ☐ both legs (diplegia)
- ☐ three extremities (triplegia)
- ☐ both arms and legs (quadriplegia)

Tonal Abnormalities

Complete this section only if the participant has received this description from a physician or other allied health professional. Leave it blank if you are unsure.

Hypotonicity (low tone) of the **trunk:**

- ☐ No
- ☐ Yes

Please select the best description of the registrant's trunk control:

- ☐ trunk upright in sitting >80% of the time
- ☐ intermittent ability to maintain trunk upright in sitting
- ☐ cannot maintain trunk in midline against gravity in upright sitting

Please select the best description of the registrant's head control:

- ☐ head upright in sitting >80% of the time
- ☐ intermittent ability to maintain head upright in sitting
- ☐ cannot maintain head in midline against gravity in upright sitting

Tone description for the **neck and/or extremities**: check all that apply.

- ☐ Hypotonia
- ☐ Hypertonia / Spasticity
- ☐ Dystonia
- ☐ Chorea, athetosis, and other hyperkinetic classifications
- ☐ Ataxia

Onset and cause of cerebral palsy:

☐ Congenital (before or during birth)	☐ Post Natal/acquired (28 days to 5-years)	☐ Unknown
☐ congenital infection (CMV, TORCH) ☐ genetic chromosomal cause ☐ malformations ☐ unknown ☐ other:_____	☐ during or following surgery or medical procedure ☐ following a seizure ☐ head injury ☐ infection ☐ near drowning ☐ near SIDS ☐ shaken baby syndrome ☐ stroke ☐ unknown ☐ other:_____	

Has MRI/Imagining been performed?

- ☐ Yes
- ☐ No

REGISTRANT ASSOCIATED CONDITIONS	
Seizure disorders/ epilepsy	☐ Unknown ☐ Neonatal only (first 28 days of life) ☐ No seizures/epilepsy ☐ No seizures in past 3 months ☐ No more than 1 seizure per month ☐ More than 1 but no more than 4 seizures per month (about one seizure per week) ☐ More than 4 seizures per month
Vision	☐ Unknown ☐ Does not need glasses/contact lenses to see well ☐ Sees well with glasses/contact lenses ☐ Difficulty seeing even with glasses ☐ Is able to detect presence/direction of a light source ☐ Is blind (cannot see light and/or hand movements)
Strabismus	☐ Yes ☐ No
Breathing	☐ Typically has normal breathing ☐ Typically needs inhaler or breathing medicines ☐ Typically requires support by CPAP, BIPAP or oxygen (no tracheostomy) ☐ Has tracheostomy ☐ Uses a ventilator
Hearing	☐ Unknown ☐ No hearing problems ☐ Hyperacuity (very sensitive hearing) ☐ Difficulty hearing but does not require hearing aid ☐ Hears with hearing aids (includes cochlear implants) ☐ Unable to hear despite hearing aids (or cochlear implants)
Understanding Language	☐ Has no difficulty understanding conversations compared to other children of the same age ☐ Has mild difficulty understanding conversations compared to other children of the same age ☐ Can understand his/her name and some short sentences, but has a lot of difficulty understanding conversations compared to other children of the same age ☐ May respond to voice but is unable to understand language ☐ Is unable to understand language ☐ Difficult or unable to assess
Communication	☐ Communicates verbally in a generally age-appropriate way; or minor limitations ☐ Communicates verbally with some difficulty; speech may be slow or somewhat difficult to understand by a new listener ☐ Communicates verbally with significant difficulty; speech is slow or quite difficult to understand by a new listener ☐ Communicates verbally with severe limitations; uses adapted technologies such as signing or an augmentative communication device ☐ Communication is severely limited even with the use of an augmentative communication device

REGISTRANT ASSOCIATED CONDITIONS (Continued)

Behavior	☐ Unknown ☐ No behavior difficulties ☐ Behavior difficulties inside the home (but not outside the home) ☐ Behavior difficulties inside and outside the home (but does not require treatment or services for behavior) ☐ Requires counseling or other services for behavior ☐ Requires counseling/other services for behavior along with ongoing medications
Food Intake	☐ Chews and swallows all regular foods by mouth ☐ Requires extra time (but still chews and swallows by mouth) ☐ Combination mouth and feeding tube (G-tube, J-tube or NG-tube) with more than half taken by mouth ☐ Combination mouth and feeding tube with less than half taken by mouth ☐ Tube fed only; nothing by mouth or for tastes only
Overall, how good would you say your child feels about him/her-self?	☐ very good ☐ above average ☐ average ☐ below average ☐ poor ☐ difficult or unable to assess
Compared with others of the same age, how physically active is your child?	☐ much less physically active ☐ less physically active ☐ about the same ☐ more physically active ☐ much more physically active
Pain in the last 4 weeks, not including pain related to procedures such as injections	☐ typically has no pain ☐ typically has mild pain that seldom (about once a month) interferes with activities ☐ typically has mild-moderate pain that sometimes (about once a week) interferes with activities ☐ typically has moderate-severe pain that often (more than once a week) interferes with activities ☐ typically has severe pain that almost always (daily) interferes with activities ☐ difficult or unable to assess
Pain location(s); *check all that apply*:	☐ headache ☐ neck ☐ chest ☐ back ☐ hip ☐ upper arm(s) ☐ elbow(s) ☐ lower arm(s) ☐ wrist(s) ☐ hand(s) ☐ thigh(s) ☐ knee(s) ☐ lower leg(s) ☐ ankle(s) ☐ feet
Urinary continence	☐ never has a daytime accident ☐ occasionally has an accident (every few months) ☐ has an accident a few times a month ☐ has an accident a few times a week ☐ has accident(s) daily

Most recent
height measurement: _____ feet and _____ inches
How was the height measure taken? ☐ In standing
☐ lying down
☐ as a calculation based on tibial length

Most recent
weight measurement: _____ pounds

Date of height/weight measurements:

REGISTRANT SURGERIES AND MEDICATIONS

Does your child have a history of hydrocephalus? ☐ Yes ☐ No

Does your child have a shunt? ☐ Yes ☐ No

What kind of medications does your child take?
Consider medications taken regularly during the last month when answering. List medications on the lines.

☐ Spasticity medication(s): _____

☐ Anti-convulsants/seizure medication(s): _____

☐ Gastrointestinal medication(s): _____

☐ Pulmonary medication(s): _____

☐ ADHD and other Behavioral medication(s): _____

☐ Other medications not listed: _____

☐ Medications that I'm not sure what they are for: _____

☐ Natural supplements: _____

☐ None

Has your child had any upper extremity (arm) surgeries? ☐ None

Month and year	Surgery type
_____	_____
_____	_____
_____	_____
_____	_____

Has your child had any lower extremity (leg) surgeries? ☐ None

Month and year	Surgery type
_____	_____
_____	_____
_____	_____
_____	_____

REGISTRANT SURGERIES AND MEDICATIONS (Continued)

Has your child had any spine surgeries? ☐ None

Month and year	Surgery type
_____	_____
_____	_____
_____	_____
_____	_____

REGISTRANT EQUIPMENT AND SERVICES

*Please consider all devices **used** in the last month. If your child owns the device, but does not use it, please do not check.*

Equipment

- ☐ manual wheelchair
- ☐ power wheelchair
- ☐ custom stroller
- ☐ bath seat
- ☐ Hoyer lift
- ☐ adapted vehicle
- ☐ walker
- ☐ crutches
- ☐ gait trainer
- ☐ cane
- ☐ stander
- ☐ ramp or chair lift for house
- ☐ other: _____
- ☐ none

Upper extremity (arm) orthotics

- ☐ hand splints
- ☐ arm immobilizers
- ☐ other: _____
- ☐ none

Lower extremity (leg) orthotics

- ☐ hip braces
- ☐ knee braces (used during the day, not at night)
- ☐ knee braces used at night for stretching
- ☐ solid AFOs (ankle foot orthoses)
- ☐ hinged AFOs (ankle-foot orthoses)
- ☐ SMOs (supra-malleolar orthoses)
- ☐ UBC insert
- ☐ other: _____
- ☐ none

Trunk orthotics

- ☐ TLSO (trunk-lumbo-sacral orthosis)
- ☐ Benik or other neoprene vest
- ☐ other: _____
- ☐ none

Augmented communication

- ☐ explain: _____
- ☐ none

Does your child have an IFSP? ☐ Yes
(Individual Family Service Plan- ages 0-3 yrs) ☐ No

Does your child have an IEP? ☐ Yes
(Individual Educational Plan- ☐ No
Special Education- ages 3-21 yrs)

REGISTRANT EQUIPMENT AND SERVICES (Continued)

Does your child have a 504 plan? *(No Special Education but receives special services, ages 3-21)*	☐ Yes ☐ No
What type of schooling does your child receive?	☐ regular classroom/regular curriculum ☐ regular classroom/some resources for regular curriculum ☐ regular classroom/modified curriculum ☐ basic life skills curriculum ☐ small or special education classroom, does not participate in grade level or life skills communication ☐ too young to enroll in school
How would you describe your child's school performance as expected for his/her age:	☐ above average ☐ average (keeps up) ☐ behind other children ☐ very far behind other children

Does your child receive therapy services?

- ☐ Physical Therapy
  - _____ minutes/week in school
  - _____minutes/week out of school
- ☐ Occupational Therapy
  - _____ minutes/week in school
  - _____minutes/week out of school
- ☐ Speech Therapy
  - _____ minutes/week in school
  - _____minutes/week out of school
- ☐ Other: _____
  - _____ minutes/week in school
  - _____minutes/week out of school
- ☐ none

Does your child participate in exercise programs?

- ☐ Dance
- ☐ Gym Facility
- ☐ Martial Arts
- ☐ Organized Sports
- ☐ Pool
- ☐ Walk/Run
- ☐ Yoga
- ☐ Other: _____
- ☐ None

Healthcare contact (optional) This person may be contacted to verify or complete details within your record, if you have allowed permission for this in your consent.	
Name:	
Type of clinician:	☐ pediatrician ☐ physiatrist ☐ neurologist ☐ physical therapist ☐ occupational therapist ☐ speech and language pathologist ☐ psychologist ☐ social worker
Phone:	
Place of work:	
Email address:	