Sri Lanka CP Register Record Form

Study Number : .....

PERSONAL DETAILS

Name of person with CP:

Sex ❒ Male ❒ Female

Age **Date of Birth** (dd/mm/yyyy)

CONTACT DETAILS and PERSON RESPONSIBLE

Name of parent/caregiver contact:

House number and Street **Village /City**

Province **District**

Telephone Number

Number of household members

Number of household rooms

Source of drinking water (tick) **Tap water** **Tube/Well** **Other**

Sanitation **Sanitary latrine** **Non-sanitary latrine** **No toilet**

Monthly family income: Rs

Person responsible for care of child with cerebral palsy (e.g. mother, grandmother etc)

ALTERNATE CONTACT

Name, address and phone number of an alternate contact in the event that the parent/caregiver person responsible can't be contacted:

Name: Relationship:

Address: Phone:

CHILD'S HEALTH PROFESSIONALS

Health professional details:
Name:
Area of specialty (e.g.paediatrician):
Hospital/organization:
Telephone number:

BIRTH DETAILS

Assisted conception used in the pregnancy

- ❒ Unassisted conception
- ❒ Fertility drugs only
- ❒ In Vitro Fertilisation (IVF)
- ❒ Other assisted conception
- ❒ Unknown
- ❒ Intracytomplasmic Sperm Injection (ICSI)
- ❒ Artificial insemination
- ❒ Gamete intrafallopian transfer (GIFT)
- ❒ Assisted conception type unknown

Place of birth

- ❒ Hospital/birth centre attached to the Hospital
  Name of hospital: _____
- ❒ Home birth planned
- ❒ Born outside home or hospital without medical assistance/ other

Province

- ❒ Eastern
- ❒ Northern
- ❒ Southern
- ❒ Western
- ❒ North Central
- ❒ North Western
- ❒ Uva
- ❒ Sabaragamu

Level of care facility of hospital of birth

- ❒ Home or hospital without neonatal intensive care unit or special care nursery
- ❒ Hospital with special care nursery
- ❒ Hospital with neonatal intensive care unit or special care nursery

Length of stay in neonatal or special care hospital of birth

- ❒ Not admitted
- ❒ Admitted

If admitted number of days ☐

Transferred to other hospital after birth?

- ❑ Yes,
  Name of hospital_____

  Province of transfer hospital:
  - ❑ Eastern
  - ❑ Northern
  - ❑ Southern
  - ❑ Western
  - ❑ North Central
  - ❑ North Western
  - ❑ Uva
  - ❑ Sabaragamu
- ❑ No
- ❑ Unknown

Level of care facility of transfer hospital

- ❒ Home or hospital without neonatal intensive care unit or special care nursery
- ❒ Hospital with special care nursery
- ❒ Hospital with neonatal intensive care unit or special care nursery

MRI completed <2 years

- ❒ Yes
- ❒ No
- ❒ Unknown

  If yes – findings were

  ❒ Normal ❒ Abnormal ❒ Unknown

MRI completed in infancy >2 years

- ❒ Yes
- ❒ No
- ❒ Unknown

  If yes – findings were

  ❒ Normal ❒ Abnormal ❒ Unknown

Number of mother's previous births prior to the birth of this child

Number of live births: ☐
Number of still births: ☐
Number of miscarriages (<20 weeks gestation): ☐

Plurality of birth

- ❒ Singleton
- ❒ Twins
- ❒ Triplets
- ❒ Quadruplets
- ❒ Quintuplets
- ❒ Sextuplets
- ❒ Other
- ❒ Unknown

Birth Order

- ❒ Singleton or first of a multiple birth
- ❒ Second of a multiple birth
- ❒ Third of a multiple birth
- ❒ Fourth of a multiple birth
- ❒ Fifth of a multiple birth
- ❒ Sixth of a multiple birth
- ❒ Other
- ❒ Unknown

Gestational Age (wks) ☐
Birth Weight (g) ☐

Birth defects

- ❒ Yes
- ❒ No
- ❒ Unknown

If yes which major category/ies of birth defect

- ❒ Nervous system
- ❒ Urogenital
- ❒ Musculoskeletal
- ❒ Cardiovascular
- ❒ Chromosomal
- ❒ Respiratory
- ❒ Metabolic
- ❒ Haemotological/Immune
- ❒ Respiratory

Early feeding difficulties (in first month of life)

- ❒ Yes
- ❒ No
- ❒ Unknown

Mode of delivery

- ❒ Vaginal delivery
- ❒ Vaginal delivery requiring forceps
- ❒ Vaginal delivery requiring vacuum delivery
- ❒ Unknown

Other details

- ❒ Breech
- ❒ Caesarean section

Delivery attended by:

- ❒ Midwife
- ❒ Doctor
- ❒ Family member
- ❒ Unknown

Signs of birth asphyxia (e.g. weak breathing, cyanosis, bradycardia)

- ❒ Yes
- ❒ No
- ❒ Unknown

Complications during child birth/labour (obstructed/prolonged/malpresentation/pre-eclamsia, haemmorrhage, premature rupture of membranes)

- ❒ Yes
- ❒ No
- ❒ Unknown

Mother experienced febrile illness during pregnancy

- ❒ Yes
- ❒ No
- ❒ Unknown

Mother received antenatal care during pregnancy

- ❒ Yes
- ❒ No
- ❒ Unknown

Mother received nutritional supplements during pregnancy (e.g. folic acid/iron)

- ❒ Yes
- ❒ No
- ❒ Unknown

BIRTH PARENTS DETAILS

Are the parents related?
❒ Yes ❒ No ❒ Unknown

Are there other family members with a disability?
❒ Yes , if yes please describe:
❒ No
❒ Unknown

Birth parent details:	Mother	Father
Date of birth (dd/mm/yyyy)		
Occupation at the time of child's birth		
Education		
No formal education		
1 year		
Grade 8		
O/L		
A/L		
Certificate		
Diploma		
Degree		
Post Graduate		
Ethnicity		
Religion		

CLINICAL DETAILS _A

Age at which motor disorder was first formally described (years/months)

By whom

Initial CP type <u>at first diagnosis</u>
❒ Spastic Monoplegia
- ❒ Left
- ❒ Right

❒ Spastic Hemiplegia
- ❒ Left
- ❒ Right

❒ Spastic Diplegia
❒ Spastic Triplegia
❒ Spastic Quadriplegia
❒ Ataxia
❒ Dyskinetic CP – mainly athetoid
❒ Dyskinetic CP – mainly dystonic
❒ Hypotonic CP
❒ Not stated

Severity as described by Gross Motor Function Classification System Level <u>at first diagnosis</u>

❒ I
❒ II
❒ III
❒ IV
❒ V
❒ Unknown

Predominant CP type ≥ 5 years

❒ Spastic Monoplegia
- ❒ Left
- ❒ Right

❒ Spastic Hemiplegia
- ❒ Left
- ❒ Right

❒ Spastic Diplegia
❒ Spastic Triplegia
❒ Spastic Quadriplegia
❒ Ataxia
❒ Dyskinetic CP – mainly athetoid
❒ Dyskinetic CP – mainly dystonic
❒ Hypotonic CP
❒ Not stated

Secondary CP type ≥ 5 years

❒ Spastic Monoplegia
- ❒ Left
- ❒ Right

❒ Spastic Hemiplegia
- ❒ Left
- ❒ Right

❒ Spastic Diplegia
❒ Spastic Triplegia
❒ Spastic Quadriplegia
❒ Ataxia
❒ Dyskinetic CP – mainly athetoid
❒ Dyskinetic CP – mainly dystonic
❒ Hypotonic CP
❒ Not stated

Severity as described by Gross Motor Function Classification System Level **≥ 5 years**

❒ I
❒ II
❒ III
❒ IV
❒ V
❒ Unknown

Severity as described by Manual Ability Classification Level at **≥ 4 years**

❒ I
❒ II
❒ III
❒ IV
❒ V
❒ Unknown

Associated Impairments/Conditions

Epilepsy ≥ 5 years

Family reports/clinician observes seizures **or** requires medication to control siezures ≥ 5 years

❒ Yes
❒ No
❒ Unknown

Intellectual Impairment ≥ 5 years

❒ Normal IQ>70
❒ Mild impairment IQ 50-69
❒ Moderate impairment IQ 35 -49
❒ Severe impairment IQ <35
❒ Probably greater than borderline impairment
❒ Probably borderline or no impairment
❒ Intellectual ability unknown

Speech impairment ≥ 5 years

❒ No impairment
❒ Some impairment
❒ Non-verbal
❒ Unknown

Visual Impairment ≥5 years

❒ No Impairment
❒ Some visual impairment (wear Glasses)
❒ Functionally blind (e.g. light perception / colour differences, see shadows but unable to use)
❒ Unknown

Strabismus status ≥5 years

❒Yes
❒ No
❒ Unknown

Hearing Impairment ≥5 years

❒ No impairment
❒ Some impairment (includes conductive loss)
❒ Bilateral Deafness
❒ Unknown

Timing and causes of CP (where known with certainty)

Pre/perinatal

❒ Genetic/chromosomal
❒ Intrauterine CMV infection
❒ Other intrauterine TORCH infection
❒ Vascular event, please describe

❒ Severe jaundice in the neonatal period (requiring exchange transfusion or multiple photo therapy)

Other definite prenatal cause please describe

Note: Events occurring in the neonatal period are likely to be associated with the intrauterine environment and therefore are not coded as postneonatal causes, with the exception of neonatal injury in an undisputedly normal infant, code as Head injury

Other pre/perinatal risk factors

❒ Maternal malnourishment
❒ Exposure to toxins during pregnancy
❒ Infant malnourishment in the neonatal period
❒ Hypoxic ichaemic encephalopathy
❒ Neonatal meningitis
❒ Neonatal sepsis

Postneonatal cause (after 28 days and before age 2 years)

Infection:
❒ Dehydration due to gastroenteritis
❒ Other bacterial infection
❒Other viral infection
❒Infection not otherwise specified

Cerebrovascular accident:
❒Associated with surgery
❒ Associated with cardiac complications (not during/post surgery)
❒ Spontaneous / other CVA

Head injury
❒Motor Vehicle Accident – Passenger in vehicle
❒Motor Vehicle Accident - Pedestrian
❒ Fall
❒Non-accidental
❒Other head injury / not otherwise specified

Other causal events:
❒Near drowning
❒Apparent life-threatening event
❒ Post-seizure
❒ Peri-operative hypoxia
❒Other postneonatal event

Any other associated syndrome that co-exists with the child's motor disability or syndrome that has a motor component which allows inclusion under the description of CP

❒ Yes if yes please state:
❒ No
❒ Unknown

CLINICAL DETAILS _B

GENERAL MOVEMENTS

General Movements Assessment, Writhing period Movements 36 weeks post-term	General Movements Assessment, Fidgety Movements at 9-20 weeks post-term
❒ Normal ❒ Abnormal ❒ Absent ❒ Unknown	❒ Normal ❒ Abnormal ❒ Absent ❒ Unknown

COMMUNICATION CLASSIFICATIONS

Viking Level ≥5 years (please circle)
Please complete Viking for <u>all cases</u>
❒ I
❒ II
❒ III
❒ IV

Communication Function Classification System (CFCS) ≥ 4 years (please circle)
❒ I
❒ II
❒ III
❒ IV
❒ V

Functional Communication Classification System (FCCS) ≥ 4 years (please circle)
❒ I
❒ II
❒ III
❒ IV
❒ V

IMMUNIZATION AND NUTRITION

Immunization
Child fully immunized
❒Yes
❒ No, if no why? _____
❒ Unknown

NUTRITION

Current weight		BMI	
Current height		Mid upper arm circumference	
SD height			
SD weight			

Eating or Drinking ≥ 5 years
❒ Standard meals
❒ Modified Diet (can only manage a modified diet e.g. soft /mashed consistencies or thickened liquids
❒Unable to eat or drink orally (requires part or complete feeding by NG tube / gastrostomy tube)

GENERAL HEALTH

Gastroesophageal reflux

❒Yes
❒ No
❒ Unknown

Number of hospitalizations for chest /respiratory infections in past 6 months: ____

SERVICES

Received rehabilitation services in last 2 years

❒ No
❒ Unknown
❒ Yes, please specify type of service/s:
❒ assistive device ❒ surgery ❒ advice
❒ therapy ❒ other

Please specify where service/s received:
❒ home based ❒ hospital ❒ not-for-profit
❒ private sector

At what age first referred for intervention ____

Main Type of intervention

❒ Active (Play based, Strengthening, etc)
❒ Passive (applying oil, massaging etc)

Receiving regular Intervention (at least once a month)

❒ Yes
❒ No
❒ Unknown

Schooling

Attending Mainstream school:
❒Yes
❒ No
❒ Unknown

Attending Special School

❒Yes
❒ No
❒ Unknown

Not attending school (6+ years <15 years):

Because:
❒ Working
❒ School is too far away to access
❒ Too costly
❒ Unable to attend because of disability (not accepted)
❒ Parent refuse to send
❒ Other

Current Medications ____

OTHER COMMENTS

Name of researcher/staff member completing interview/data collection:

Date completed: ____ ____ ____