



THE CDG FAMILY NETWORK

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Authorization for Use and Release of Medical and Statistical Data

I hereby authorize the CDG Family Network to use any and all medical records and statistical data including, but not limited to, information concerning: diagnoses, conditions; treatments; educational programs; and therapeutic services, of _____ (Parents and Child) collected as a result of responses to survey questionnaires and follow up interviews. I further authorize the CDG Family Network to release such information, as necessary, to its selected clinical researchers and healthcare providers for the exclusive purpose of statistical and medical research.

Parent(s)' or Guardian(s)' Name(s)

Child's Name

Father's or Guardian(s)' Signature

Mother's or Guardian(s)' Signature

Name of Child: _____

Questionnaire completed by: _____

Relationship to child: _____

MAILING INFORMATION

First name: _____ Last Name: _____

Spouse's name: _____

Address: _____

City: _____ State: _____ Zip code: _____

Home Phone: _____ Cell Phone: _____

E-mail Address: _____

NUMBER OF CHILDREN

Total pregnancies _____ Living _____ Miscarriages _____ Stillborn _____ Died _____

Multiples (e.g. twins) _____

ETHNIC BACKGROUND

African _____ Asian _____ European _____ Hispanic _____ Middle Eastern _____

Native American _____ Other (specify) _____

Are parents related? Yes, closely [] Yes, distantly [] No []

CHILD INFORMATION

Date of birth ___/___/___ Male _____ Female _____

Has your child in the past had any specified medical diagnosis (e.g. cystic fibrosis, cerebral palsy, CDG etc)? Yes [] No []

If yes, print diagnoses in chronological order and check the appropriate box.

Diagnosis	Diagnosed at what age						
	0-1 mth	1-3 mth	3-6 mth	6-12 mth	1-3 yrs	3-5 yrs	>5 yrs
1. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Does your child carry any current diagnosis? Yes [] No []

If yes, which one? _____

PREGNANCY INFORMATION

Did the doctors tell you that mother had too much fluid (polyhydramnios)? Yes [] No []

Did the doctors tell you that the fetus had edema (fetal hydrops)? Yes [] No []

Were any of the following prenatal diagnostic tests performed?

Ultrasound 1 Yes, normal [] Yes, abnormal [] No []

Ultrasound 2 Yes, normal [] Yes, abnormal [] No []

Amniocentesis Yes, normal [] Yes, abnormal [] No []

α-Fetoprotein Yes, normal [] Yes, abnormal [] No []

Did mother suffer from any medical conditions during pregnancy? Yes [] No []

If yes, which one(s)? _____

DELIVERY INFORMATION

How was your child delivered? Vaginally [] C-section []

If C-section, reason? _____

Length of pregnancy (wks) _____

NEWBORN INFORMATION

If known, Apgar score at birth ___/___

Birth weight _____ Birth length _____ Birth head circumference _____

Symptoms noted at birth and early after?

- | | |
|-------------------------|---|
| Failure to thrive | Yes [] No [] |
| Weak sucking | Yes [] No [] |
| Facial abnormalities | Yes [] No [] |
| Eye wandering | Yes [] No [] |
| Inverted nipples | Yes [] No [] |
| Seizures | Yes, frequent [] Yes, few [] No, none [] |
| Pericardial effusion | Yes [] No [] |
| Reflux | Yes [] No [] |
| Apnea | Yes [] No [] |
| Uneven fat distribution | Yes [] No [] |
| Fat pads | Yes [] No [] |
| Skin dimpling | Yes [] No [] |
| Liver enlargement | Yes [] No [] |
| Clotting problems | Yes [] No [] |
| Kidney problems | Yes [] No [] |
| Floppiness | Yes [] No [] |

DIAGNOSTIC TEST INFORMATION

Has your child ever had any of the following performed?

- | | |
|---------------------------------|--|
| MRI | Yes, normal [] Yes, abnormal [] No [] |
| EMG (electromyography) | Yes, normal [] Yes, abnormal [] No [] |
| NCV (nerve conduction velocity) | Yes, normal [] Yes, abnormal [] No [] |
| Muscle biopsy | Yes, normal [] Yes, abnormal [] No [] |
| Metabolic Screen | Yes, normal [] Yes, abnormal [] No [] |
| EEG (electroencephalogram) | Yes, normal [] Yes, abnormal [] No [] |

Have you consulted any of the following types of pediatric specialists because of your child's symptoms?

If yes, at what age was the first visit?

	Yes	No	0-1 mth	1-3 mth	3-6 mth	6-12 mth	1-3 yrs	3-5 yrs	>5 yrs
Neurologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cardiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart surgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthopedic surgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurosurgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Geneticist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pulmonary specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immunologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Endocrinologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oncologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General pediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Has your child ever been IQ-tested? Yes [] No [] If yes, IQ _____

CLINICAL COURSE

How are you child's motor skills concerning

Fine motor skills (e.g. playing with toys, using hands in solving tasks, etc)

Normal [] Slightly impaired [] Largely impaired [] Missing []

Gross motor skills

Sitting Normal [] With aid [] Does not sit up []

Standing Normal [] Stands with aid [] Does not stand up []

Mobility Walks [] Walks with aid [] Crawls [] Immobile []

What is your child's vision like? Normal [] Slightly impaired [] Largely impaired [] Blind []

Has your doctor ever mentioned any of the following terms concerning your child's vision?

- | | |
|----------------------|----------------|
| Nystagmus | Yes [] No [] |
| Stabismus | Yes [] No [] |
| Estropia | Yes [] No [] |
| Retinitis Pigmentosa | Yes [] No [] |
| Ocular Motor Apraxia | Yes [] No [] |

How is your child's hearing? Normal [] Impaired [] Deaf []

Has your child ever had problems with his/her growth rate? Yes [] No []

Have you ever heard your child's doctor use any of the following terms concerning your child?

- | | |
|------------------------------|----------------|
| Cerebellar hypoplasia | Yes [] No [] |
| Microcephaly | Yes [] No [] |
| Seizures | Yes [] No [] |
| Stroke-like episodes | Yes [] No [] |
| Ataxia | Yes [] No [] |
| Optic nerve atrophy | Yes [] No [] |
| Olivopontocerebellar atrophy | Yes [] No [] |
| Hypotonia | Yes [] No [] |
| Large ears | Yes [] No [] |
| Facial abnormalities | Yes [] No [] |
| Limb joint restriction | Yes [] No [] |
| Thoracic spinal deformities | Yes [] No [] |
| Undescended testes | Yes [] No [] |
| Hernias | Yes [] No [] |
| Liver disease | Yes [] No [] |
| Liver enlargement | Yes [] No [] |
| Congenital hepatic fibrosis | Yes [] No [] |
| Ascites | Yes [] No [] |

- | | |
|---|----------------|
| Protein-losing enteropathy | Yes [] No [] |
| Dehydration | Yes [] No [] |
| Bouts of vomiting/diarrhea | Yes [] No [] |
| Disseminated intravascular coagulation (DIC) | Yes [] No [] |
| Bleeding disorders | Yes [] No [] |
| Gastrointestinal bleeding | Yes [] No [] |
| Reflux | Yes [] No [] |
| Pericardial effusion | Yes [] No [] |
| Cardiomyopathy | Yes [] No [] |
| Hypoglycemia | Yes [] No [] |
| Kidney disease | Yes [] No [] |
| Osteopenia | Yes [] No [] |
| Feeding difficulties | Yes [] No [] |
| Fat pads | Yes [] No [] |
| Lipodystrophy | Yes [] No [] |
| Inverted breast nipples | Yes [] No [] |
| Immunodeficiency | Yes [] No [] |
| Thyroid disease | Yes [] No [] |

The CDG Family Network and co-workers thank you for taking your time to fill out this form. Your help is invaluable.

SIGNATURE _____ **DATE** _____