



ENRAH Questionnaire
Version V6.3 - July 2006

ENRAH for SMEs Project
Funded by the European Commission, FP6 2005-2007

Questionnaire
for the AHC Registry

Version 6.3



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Treating Physician

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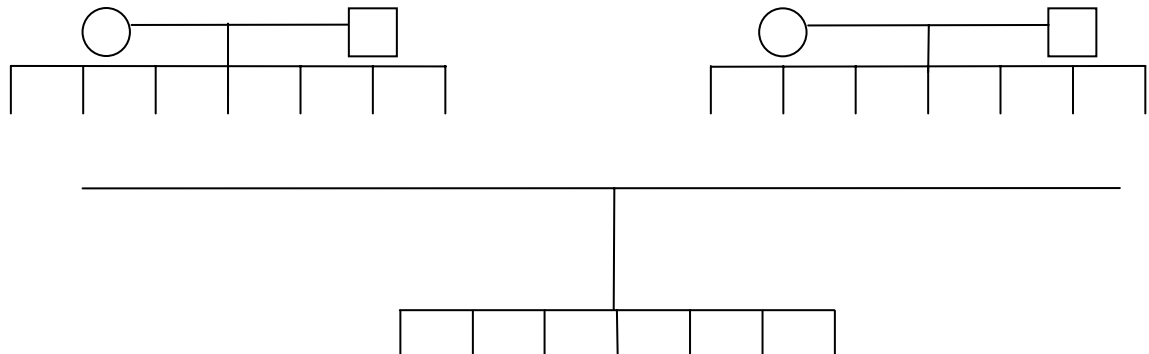
Patient Code Provided by the Center

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Other Information

| | | |
|-------|--|--|
| G0.0 | Patient HC Forum Identifier | |
| G0.1 | Patient Birth Date (dd.mm.yyyy) | |
| G0.2 | Date of inclusion to the database (dd.mm.yyyy) | |
| G0.3 | Date the diagnosis of HA was made (dd.mm.yyyy) | |
| G0.4 | Pregnancy (0= normal; 1= abnormal; 888=unknown) | |
| G0.5 | Delivery (0=vaginal delivery; 1= sectio caesarea; 888=unknown) | |
| G0.6 | Apgar (0= >8; 1= <=7; 888=unknown) | |
| G0.7 | Age of Death (0=alive;1=0-2; 2=2-6; 3=6-12; 4=12-18; 5= >18) | |
| G0.8 | Age of first paroxysmal event (month; 777=no event; 888=unknown) | |
| G0.9 | Age of first onset of plegic attacks (month; 888=unknown) | |
| G0.10 | Age of definitely epileptic seizures (month; 777=no seizures; 888=unknown) | |
| G0.11 | First or second degree consanguinity (0=no; 1=yes; 888=unknown) | |
| G0.12 | Migraine in the family* (0=no; 1=yes; 888=unknown) | |
| G0.13 | Epilepsy in the family* (0=no; 1=yes; 888=unknown) | |
| G0.14 | Other paroxysmal disorders in the family* (0=no; 1=yes; 888=unknown) | |
| G0.15 | Other neurological disease in the family* (0=no; 1=yes; 888=unknown) | |
| G0.16 | Mortality in childhood in the family* (0=no; 1=yes; 888=unknown) | |
| G0.17 | Comorbidity in the family* (0=no; 1=yes; 888=unknown) | |
| | * at least in parents and grand parents | |
| G0.18 | In your opinion, as a treating physician or child neurologist, is this a typical case of AHC? (0= no, atypical; 1=yes; 888=unknown) | |
| G0.19 | In your opinion, as a data collector, is this a typical case of AHC? (0= no, atypical; 1=yes; 888=unknown) | |

G0.20 FAMILY TREE



Comments:



| | | |
|--------------|--|--|
| G1.0 | PAROXYSMAL EVENTS (0=no; 1=yes) | |
| G1.1 | Premonitory signs or aura (0=no; 1=yes; 888=unknown) | |
| G1.2 | Tonic/dystonic attacks (0=no; 1=yes; 888=unknown) | |
| G1.3 | Plegic attacks (0=no; 1=yes; 888=unknown) | |
| G1.4 | Abnormal ocular movements (0=no; 1=yes; 888=unknown) | |
| G1.5 | Gait unsteadiness (0=no; 1=yes; 888=unknown) | |
| G1.6 | Seizures/Epilepsy (0=no; 1=yes; 888=unknown) | |
| G1.7 | Status epilepticus (0=no; 1=yes; 888=unknown) | |
| G1.8 | Headache (0=no; 1=yes, not migrainious; 2=yes, migrainious; 3= yes, unspecified; 888=unknown) | |
| G1.9 | Autonomic dysfunctions (0=no; 1=yes; 888=unknown) | |
| G1.10 | Breathing difficulties (0=no; 1=yes; 888=unknown) | |
| G1.11 | Pain (0=no; 1=yes; 888=unknown) | |
| G1.12 | Disappearance of symptoms with sleep and immediately following sleep (0=no; 1=yes; 888=unknown) | |

| | | |
|--------------|--|--|
| G2.0 | NON PAROXYSMAL FEATURES (0=no; 1=yes) | |
| G2.1 | Gait unsteadiness (0=no; 1=yes; 888=unknown) | |
| G2.2 | Gross Motor problems (0=no; 1=yes; 888=unknown) | |
| G2.3 | Fine motor problems (0=no; 1=yes; 888=unknown) | |
| G2.4 | Pyramidal signs (0=no; 1=yes; 888=unknown) | |
| G2.5 | Dystonia (0=no; 1=yes; 888=unknown) | |
| G2.6 | Myoclonus (0=no; 1=yes; 888=unknown) | |
| G2.7 | Chorea (0=no; 1=yes; 888=unknown) | |
| G2.8 | Tremor (0=no; 1=yes; 888=unknown) | |
| G2.9 | Complex-/other Movement Disorder (0=no; 1=yes; 888=unknown) | |
| G2.10 | Muscle Tone (0=normal; 1= hypertonia; 2= hypotonia; 888=unknown) | |
| G2.11 | Mental retardation (0=no; 1=yes; 888=unknown) | |
| G2.12 | Cognitive dysfunction(0=no; 1=yes; 888=unknown) | |
| G2.13 | Communication disorders (0=no; 1=yes; 888=unknown) | |
| G2.14 | Behavioural disorders (0=no; 1=yes; 888=unknown) | |
| G2.15 | Educational placement (0=normal without help; 1=normal with help; 2=special course; 777=not applicable; 888=unknown) | |
| G2.16 | School attendance (0=more than 90%; 1=90-50%; 2=less than 50%; 777=not applicable; 888=unknown) | |
| G2.17 | Working employment (0=autonomous ; 1=with assistance; 2=no; 777=not applicable; 888=unknown) | |



OTHER INFORMATION:

G3.1 ETHNIC ASPECTS:

G3.2 GROWTH AND SOMATIC COMPLAINS :

G3.3 feedings problems (0=no; 1=yes; 888=unknown)

G3.4 gastrostomy (0=no; 1=yes; 888=unknown)

G3.5 weight centiles (0=<2; 1=2-10; 2=10-25; 3=25-50; 4=50-75; 5=75-90; 6=90-98; 7=>98; 888=unknown)

G3.6 height centiles (0=<2; 1=2-10; 2=10-25; 3=25-50; 4=50-75; 5=75-90; 6=90-98; 7=>98; 888=unknown)

G3.7 hip dysfunction (0=no; 1=yes; 888=unknown):

G3.8 cardiac involvement (0=no; 1=yes; 888=unknown):

G3.9 respiratory involvement (0=no; 1=yes; 888=unknown)

G3.10 ANY PROBLEMS FOLLOWING ANESTHESIA OR VACCINATION:

G3.11 COMORBIDITY:

[Index](#)



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 1/3

| | | |
|----------------|--|--|
| F1.1.0 | TONIC OR DYSTONIC ATTACKS (0=no; 1=yes) | |
| F1.1.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.1.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 888=unknown) | |
| F1.1.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.1.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.10 | Other effective measures (0=no; 1=yes; 888=unknown) *link to the open window | |
| F1.1.11 | Trigger events (0=no; 1= yes; 888=unknown) | |

| | | |
|----------------|--|--|
| F1.2.0 | PLEGIC ATTACKS (0=no; 1=yes) | |
| F1.2.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.2.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 3= both sides; 888=unknown) | |
| F1.2.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.2.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.10 | Other effective measures (0=no; 1=yes; 888=unknown)*link to the open window | |
| F1.2.11 | Trigger events (0=no; 1= yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 2/3

| | | |
|---------------|--|--|
| F1.3.0 | ABNORMAL OCULAR MOVEMENTS (0=no; 1=yes) | |
| F1.3.1 | Semiology (0=simple; 1=complex; 888=unknown) | |
| F1.3.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.4 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.5 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.6 | Any effective drugs for acute attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.7 | Any effective prophylaxis for non epileptic attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.8 | Trigger events (0=no; 1= yes; 888=unknown) | |
| F1.3.9 | Are they linked to an other paroxysmal event? (0= no; 1= sometimes; 2=always; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.4.0 | SEIZURES (0=no; 1=yes) | |
| F1.4.1 | Semiology (0=focal, with or without secondary generalization; 1=generalized; 2=focal and generalized; 888=unknown) | |
| F1.4.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.4 | Any effective drugs for ongoing seizure ? (0=no; 1=yes; 888=unknown) | |
| F1.4.5 | Any effective drug for chronic treatment? (0=no; 1=yes;888=unknown) | |
| F1.4.6 | Is it timely linked to an other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.5.0 | STATUS EPILEPTICUS (0=no; 1=yes) | |
| F1.5.1 | Semiology (0=convulsive; 1=not convulsive; 3=both; 888=unknown) | |
| F1.5.2 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.6.0 | HEADACHE (0=no; 1=yes) | |
| F1.6.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.7.0 | AUTONOMIC DYSFUNCTION (0=no; 1=yes) | |
| F1.7.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.7.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 3/3

| | | |
|---------------|--|--|
| F1.8.0 | BREATHING DIFFICULTIES (0=no; 1=yes) | |
| F1.8.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.8.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.9.0 | PAIN (0=no; 1=yes) | |
| F1.9.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.9.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

COMMENTS

F1.10.0 Any significant problems in managing attacks in school?

F1.10.1 Other effective measures to treat the non-epileptic attacks?

F1.10.2 Additional information about semiology of paroxysmal events:

F1.10.3 Other Information about paroxysmal events:



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 1/2

| | | |
|----------------|--|--|
| F2.1.0 | NEUROLOGICAL DYSFUNCTION (0=no; 1=yes) | |
| F2.1.1 | Walking at home (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.2 | Walking outdoors (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.3 | Gait unsteadiness (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.4 | Gross Motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown;) | |
| F2.1.5 | Fine motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888= unknown) | |
| F2.1.6 | Pyramidal signs (0=normal; 1= increased; 2=reduced; 777= not applicable; 888=unknown) | |
| F2.1.7 | Dystonia (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.8 | Myoclonus (0= no; 1=yes, mild; 2= yes moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.9 | Chorea (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.10 | Tremor (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.11 | Complex Movement Disorder (0=no; 1=yes, mild; 2= yes moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.12 | Muscle Tone (0=normal; 1= hypertonia; 2= hypotonia; 777= not applicable; 888=unknown) | |
| F2.2.0 | MENTAL RETARDATION (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.0 | COGNITIVE DYSFUNCTION (0=no; 1=yes) | |
| F2.3.1 | Attention (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.2 | Memory (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.3 | Visuospatial (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.4 | Visuomotor (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.0 | COMMUNICATION DISORDER (0=no; 1=yes) | |
| F2.4.1 | Verbal Communication (0=no; 1=yes mild; 2= yes, moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.2 | Gestual Communication (0=no; 1=yes; 777= not applicable; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 2/2

| | | |
|---------------|---|--|
| F2.5.0 | LEARNING DISABILITIES (0=no; 1=yes) | |
| F2.5.1 | Dyslexia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.2 | Dyscalculia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.3 | Dysgraphia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |

| | | |
|---------------|---|--|
| F2.6.0 | BEHAVIOURAL DISORDERS (0=no; 1=yes; 888=unknown) | |
| F2.6.1 | Behavioural Disorders Details: | |

| | |
|---------------|------------------|
| F2.7.0 | COMMENTS: |
|---------------|------------------|



Date: _____

Patient Code provided by the center: _____

INVESTIGATIONS 1/1

| LABORATORY INVESTIGATION (0=normal; 1=not normal; 999= not done) | | | NEURORADIOLOGICAL AND NEUROPHYSIOLOGICAL INVESTIGATION (0=normal; 1=not normal; 999= not done) | | |
|---|-------------------------------|--|--|---|--|
| F3.1.1 | Base screening | | F3.2.1 | CT scan | |
| F3.1.2 | Blood Lactate | | F3.2.2 | MRI scan | |
| F3.1.3 | Blood Pyruvate | | F3.2.3 | Interictal SPECT | |
| F3.1.4 | CPK | | F3.2.4 | Ictal SPECT | |
| F3.1.5 | Blood Ammonium | | F3.2.5 | PET (*) | |
| F3.1.6 | Lysosomal enzymes | | F3.2.6 | MRI angiography | |
| F3.1.7 | Blood Amino acids | | F3.2.7 | MRI spectroscopy | |
| F3.1.8 | Blood (Urine) Organic acids | | F3.2.8 | Ictal EEG (during epileptic seizure) | |
| F3.1.9 | VLFA | | F3.2.9 | Paroxysmal EEG (during non epileptic attack) | |
| F3.1.10 | CDG | | F3.2.10 | Interictal EEG | |
| F3.1.11 | Purine, pyrimidine | | F3.2.11 | VEP | |
| F3.1.12 | Antiphospholipid | | F3.2.12 | BAEP | |
| F3.1.13 | Ana (anti nuclear antibodies) | | F3.2.13 | SEP | |
| F3.1.14 | CSF (standard examination) | | F3.2.14 | EMG | |
| F3.1.15 | CSF neurotransmitters | | F3.2.15 | ENG | |
| F3.1.16 | CSF pyruvate | | F3.2.16 | Blink reflexes | |
| F3.1.17 | CSF lactate | | F3.2.17 | ECG | |
| F3.1.18 | CSF amino acids | | F3.2.18 | Echocardiogram | |
| F3.1.19 | Muscle Biopsy | | F3.2.19 | Eye Fundus | |
| F3.1.20 | Mitochondrial chain analysis | | | (*) If "Yes" precise the tracer used : | |
| F3.1.21 | Skin Biopsy | | | | |
| F3.1.22 | Urine oligosaccharide | | | | |
| F3.1.23 | Urine mucopolysaccharide | | | | |
| F3.1.24 | Caryotype | | | | |
| F3.1.25 | Telomere analysis | | | | |

COMMENTS:

F3.3.1 Other genetic studies: (0=no; 1=yes)

F3.3.2 Other genetic studies details:

F3.4.1 Other biochemical studies: (0=no; 1=yes)

F3.4.2 Other biochemical studies details:

F3.5.1 Other instrumental investigations: (0=no; 1=yes)

F3.5.2 Other instrumental investigations details:



Date: _____

Patient Code provided by the center: _____

| TREATMENT 1/2 (A - L) | | | | | | | | |
|-----------------------|------------------------------|----|-----|-----|------|----|---|----|
| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
| F4.1.1 | Acetazolamide | | | | | | | |
| F4.1.2 | Alprazolam | | | | | | | |
| F4.1.3 | Baclofen | | | | | | | |
| F4.1.4 | Barbexaclone | | | | | | | |
| F4.1.5 | Biperiden | | | | | | | |
| F4.1.6 | Bromocriptine | | | | | | | |
| F4.1.7 | Buspirone | | | | | | | |
| F4.1.8 | Carbamazepine | | | | | | | |
| F4.1.9 | Chloral Hydrate | | | | | | | |
| F4.1.10 | Cinarizine | | | | | | | |
| F4.1.11 | Ciproterone-ethinylestradiol | | | | | | | |
| F4.1.12 | Clobazam | | | | | | | |
| F4.1.13 | Clonazepam | | | | | | | |
| F4.1.14 | Clonidine | | | | | | | |
| F4.1.15 | Diazepam | | | | | | | |
| F4.1.16 | Dihydroergotamine | | | | | | | |
| F4.1.17 | Ergotamine | | | | | | | |
| F4.1.18 | Ethosuximide | | | | | | | |
| F4.1.19 | Felbamate | | | | | | | |
| F4.1.20 | Flunarizine | | | | | | | |
| F4.1.21 | Fluoxetine | | | | | | | |
| F4.1.22 | Gabapentin | | | | | | | |
| F4.1.23 | Haloperidol | | | | | | | |
| F4.1.24 | Lamotrigine | | | | | | | |
| F4.1.25 | L-dopa + carbidopa | | | | | | | |
| F4.1.26 | Levetiracetam | | | | | | | |
| F4.1.27 | Lorazepam | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=unneffective; 1=effective; 999= not used; SE (side effects); 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

TREATMENT 2/2 (M - Z)

| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
|---------|-----------------|----|-----|-----|------|----|---|----|
| F4.1.28 | Melatonin | | | | | | | |
| F4.1.29 | Metoclopramide | | | | | | | |
| F4.1.30 | Methylphenidate | | | | | | | |
| F4.1.31 | Methysergide | | | | | | | |
| F4.1.32 | Midazolam | | | | | | | |
| F4.1.33 | Niaprazine | | | | | | | |
| F4.1.34 | Nimodipine | | | | | | | |
| F4.1.35 | Nitrazepam | | | | | | | |
| F4.1.36 | Oxcarbazepine | | | | | | | |
| F4.1.37 | Phenytoin | | | | | | | |
| F4.1.38 | Phenobarbital | | | | | | | |
| F4.1.39 | Pimozide | | | | | | | |
| F4.1.40 | Piracetam | | | | | | | |
| F4.1.41 | Pregabalin | | | | | | | |
| F4.1.42 | Primidone | | | | | | | |
| F4.1.43 | Propranolol | | | | | | | |
| F4.1.44 | Sertraline | | | | | | | |
| F4.1.45 | Sulthiame | | | | | | | |
| F4.1.46 | Sumatriptan | | | | | | | |
| F4.1.47 | Tiagabine | | | | | | | |
| F4.1.48 | Topiramate | | | | | | | |
| F4.1.49 | Trazodone | | | | | | | |
| F4.1.50 | Trixyphenidyl | | | | | | | |
| F4.1.51 | Tript-OH | | | | | | | |
| F4.1.52 | Valproate | | | | | | | |
| F4.1.53 | Vigabatrin | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=uneffective; 1=effective; 999= not used; SE (side effects) ; 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

TRIGGER EVENTS 1/1

(0=no; 1=yes; 888=unknown)

| | | |
|--------|-----------------------------|--|
| F5.1.1 | Stress | |
| F5.1.2 | Bathing | |
| F5.1.3 | Temperature | |
| F5.1.4 | Excitement | |
| F5.1.5 | Food | |
| F5.1.6 | Sunlight | |
| F5.1.7 | fluorescent light | |
| F5.1.8 | specific activities | |
| F5.1.9 | specific activities details | |

FURTHER INFORMATION

F6.1.0 FURTHER INFORMATION:

[Index](#)



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 1/3

| | | |
|----------------|--|--|
| F1.1.0 | TONIC OR DYSTONIC ATTACKS (0=no; 1=yes) | |
| F1.1.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.1.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 888=unknown) | |
| F1.1.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.1.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.10 | Other effective measures (0=no; 1=yes; 888=unknown) *link to the open window | |
| F1.1.11 | Trigger events (0=no; 1= yes; 888=unknown) | |

| | | |
|----------------|--|--|
| F1.2.0 | PLEGIC ATTACKS (0=no; 1=yes) | |
| F1.2.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.2.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 3= both sides; 888=unknown) | |
| F1.2.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.2.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.10 | Other effective measures (0=no; 1=yes; 888=unknown)*link to the open window | |
| F1.2.11 | Trigger events (0=no; 1= yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 2/3

| | | |
|---------------|--|--|
| F1.3.0 | ABNORMAL OCULAR MOVEMENTS (0=no; 1=yes) | |
| F1.3.1 | Semiology (0=simple; 1=complex; 888=unknown) | |
| F1.3.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.4 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.5 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.6 | Any effective drugs for acute attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.7 | Any effective prophylaxis for non epileptic attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.8 | Trigger events (0=no; 1= yes; 888=unknown) | |
| F1.3.9 | Are they linked to an other paroxysmal event? (0= no; 1= sometimes; 2=always; 888=unknown) | |
| F1.4.0 | SEIZURES (0=no; 1=yes) | |
| F1.4.1 | Semiology (0=focal, with or without secondary generalization; 1=generalized; 2=focal and generalized; 888=unknown) | |
| F1.4.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.4 | Any effective drugs for ongoing seizure ? (0=no; 1=yes; 888=unknown) | |
| F1.4.5 | Any effective drug for chronic treatment? (0=no; 1=yes;888=unknown) | |
| F1.4.6 | Is it timely linked to an other paroxysmal event? (0= no; 1= yes; 888=unknown) | |
| F1.5.0 | STATUS EPILEPTICUS (0=no; 1=yes) | |
| F1.5.1 | Semiology (0=convulsive; 1=not convulsive; 3=both; 888=unknown) | |
| F1.5.2 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.0 | HEADACHE (0=no; 1=yes) | |
| F1.6.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |
| F1.7.0 | AUTONOMIC DYSFUNCTION (0=no; 1=yes) | |
| F1.7.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.7.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 3/3

| | | |
|---------------|--|--|
| F1.8.0 | BREATHING DIFFICULTIES (0=no; 1=yes) | |
| F1.8.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.8.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.9.0 | PAIN (0=no; 1=yes) | |
| F1.9.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.9.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

COMMENTS

F1.10.0 Any significant problems in managing attacks in school?

F1.10.1 Other effective measures to treat the non-epileptic attacks?

F1.10.2 Additional information about semiology of paroxysmal events:

F1.10.3 Other Information about paroxysmal events:



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 1/2

| | | |
|----------------|--|--|
| F2.1.0 | NEUROLOGICAL DYSFUNCTION (0=no; 1=yes) | |
| F2.1.1 | Walking at home (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.2 | Walking outdoors (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.3 | Gait unsteadiness (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.4 | Gross Motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown;) | |
| F2.1.5 | Fine motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888= unknown) | |
| F2.1.6 | Pyramidal signs (0=normal; 1= increased; 2=reduced; 777= not applicable; 888=unknown) | |
| F2.1.7 | Dystonia (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.8 | Myoclonus (0= no; 1=yes, mild; 2= yes moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.9 | Chorea (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.10 | Tremor (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.11 | Complex Movement Disorder (0=no; 1=yes, mild; 2= yes moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.12 | Muscle Tone (0=normal; 1= hypertonia; 2= hypotonia; 777= not applicable; 888=unknown) | |
| F2.2.0 | MENTAL RETARDATION (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.0 | COGNITIVE DYSFUNCTION (0=no; 1=yes) | |
| F2.3.1 | Attention (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.2 | Memory (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.3 | Visuospatial (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.4 | Visuomotor (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.0 | COMMUNICATION DISORDER (0=no; 1=yes) | |
| F2.4.1 | Verbal Communication (0=no; 1=yes mild; 2= yes, moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.2 | Gestual Communication (0=no; 1=yes; 777= not applicable; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 2/2

| | | |
|---------------|---|--|
| F2.5.0 | LEARNING DISABILITIES (0=no; 1=yes) | |
| F2.5.1 | Dyslexia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.2 | Dyscalculia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.3 | Dysgraphia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |

| | | |
|---------------|---|--|
| F2.6.0 | BEHAVIOURAL DISORDERS (0=no; 1=yes; 888=unknown) | |
| F2.6.1 | Behavioural Disorders Details: | |

| | |
|---------------|------------------|
| F2.7.0 | COMMENTS: |
|---------------|------------------|



Date: _____

Patient Code provided by the center: _____

INVESTIGATIONS 1/1

| LABORATORY INVESTIGATION (0=normal; 1=not normal; 999= not done) | | |
|---|-------------------------------|--|
| F3.1.1 | Base screening | |
| F3.1.2 | Blood Lactate | |
| F3.1.3 | Blood Pyruvate | |
| F3.1.4 | CPK | |
| F3.1.5 | Blood Ammonium | |
| F3.1.6 | Lysosomal enzymes | |
| F3.1.7 | Blood Amino acids | |
| F3.1.8 | Blood (Urine) Organic acids | |
| F3.1.9 | VLFA | |
| F3.1.10 | CDG | |
| F3.1.11 | Purine, pyrimidine | |
| F3.1.12 | Antiphospholipid | |
| F3.1.13 | Ana (anti nuclear antibodies) | |
| F3.1.14 | CSF (standard examination) | |
| F3.1.15 | CSF neurotransmitters | |
| F3.1.16 | CSF pyruvate | |
| F3.1.17 | CSF lactate | |
| F3.1.18 | CSF amino acids | |
| F3.1.19 | Muscle Biopsy | |
| F3.1.20 | Mitochondrial chain analysis | |
| F3.1.21 | Skin Biopsy | |
| F3.1.22 | Urine oligosaccharide | |
| F3.1.23 | Urine mucopolysaccharide | |
| F3.1.24 | Caryotype | |
| F3.1.25 | Telomere analysis | |

| NEURORADIOLOGICAL AND NEUROPHYSIOLOGICAL INVESTIGATION (0=normal; 1=not normal; 999= not done) | | |
|--|--|--|
| F3.2.1 | CT scan | |
| F3.2.2 | MRI scan | |
| F3.2.3 | Interictal SPECT | |
| F3.2.4 | Ictal SPECT | |
| F3.2.5 | PET (*) | |
| F3.2.6 | MRI angiography | |
| F3.2.7 | MRI spectroscopy | |
| F3.2.8 | Ictal EEG (during epileptic seizure) | |
| F3.2.9 | Paroxysmal EEG (during non epileptic attack) | |
| F3.2.10 | Interictal EEG | |
| F3.2.11 | VEP | |
| F3.2.12 | BAEP | |
| F3.2.13 | SEP | |
| F3.2.14 | EMG | |
| F3.2.15 | ENG | |
| F3.2.16 | Blink reflexes | |
| F3.2.17 | ECG | |
| F3.2.18 | Echocardiogram | |
| F3.2.19 | Eye Fundus | |
| | (*) If "Yes" precise the tracer used : | |
| | | |

COMMENTS:

F3.3.1 Other genetic studies: (0=no; 1=yes)

F3.3.2 Other genetic studies details:

F3.4.1 Other biochemical studies: (0=no; 1=yes)

F3.4.2 Other biochemical studies details:

F3.5.1 Other instrumental investigations: (0=no; 1=yes)

F3.5.2 Other instrumental investigations details:



Date: _____

Patient Code provided by the center: _____

TREATMENT 1/2 (A - L)

| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
|---------|------------------------------|----|-----|-----|------|----|---|----|
| F4.1.1 | Acetazolamide | | | | | | | |
| F4.1.2 | Alprazolam | | | | | | | |
| F4.1.3 | Baclofen | | | | | | | |
| F4.1.4 | Barbexaclone | | | | | | | |
| F4.1.5 | Biperiden | | | | | | | |
| F4.1.6 | Bromocriptine | | | | | | | |
| F4.1.7 | Buspirone | | | | | | | |
| F4.1.8 | Carbamazepine | | | | | | | |
| F4.1.9 | Chloral Hydrate | | | | | | | |
| F4.1.10 | Cinarizine | | | | | | | |
| F4.1.11 | Ciproterone-ethinylestradiol | | | | | | | |
| F4.1.12 | Clobazam | | | | | | | |
| F4.1.13 | Clonazepam | | | | | | | |
| F4.1.14 | Clonidine | | | | | | | |
| F4.1.15 | Diazepam | | | | | | | |
| F4.1.16 | Dihydroergotamine | | | | | | | |
| F4.1.17 | Ergotamine | | | | | | | |
| F4.1.18 | Ethosuximide | | | | | | | |
| F4.1.19 | Felbamate | | | | | | | |
| F4.1.20 | Flunarizine | | | | | | | |
| F4.1.21 | Fluoxetine | | | | | | | |
| F4.1.22 | Gabapentin | | | | | | | |
| F4.1.23 | Haloperidol | | | | | | | |
| F4.1.24 | Lamotrigine | | | | | | | |
| F4.1.25 | L-dopa + carbidopa | | | | | | | |
| F4.1.26 | Levetiracetam | | | | | | | |
| F4.1.27 | Lorazepam | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=**uneffective**; 1=**effective**; 999= **not used**; SE (side effects) ; 0=**no**; 1=**yes**; 888=**unknown**



Date: _____

Patient Code provided by the center: _____

TREATMENT 2/2 (M - Z)

| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
|---------|-----------------|----|-----|-----|------|----|---|----|
| F4.1.28 | Melatonin | | | | | | | |
| F4.1.29 | Metoclopramide | | | | | | | |
| F4.1.30 | Methylphenidate | | | | | | | |
| F4.1.31 | Methysergide | | | | | | | |
| F4.1.32 | Midazolam | | | | | | | |
| F4.1.33 | Niaprazine | | | | | | | |
| F4.1.34 | Nimodipine | | | | | | | |
| F4.1.35 | Nitrazepam | | | | | | | |
| F4.1.36 | Oxcarbazepine | | | | | | | |
| F4.1.37 | Phenytoin | | | | | | | |
| F4.1.38 | Phenobarbital | | | | | | | |
| F4.1.39 | Pimozide | | | | | | | |
| F4.1.40 | Piracetam | | | | | | | |
| F4.1.41 | Pregabalin | | | | | | | |
| F4.1.42 | Primidone | | | | | | | |
| F4.1.43 | Propranolol | | | | | | | |
| F4.1.44 | Sertraline | | | | | | | |
| F4.1.45 | Sulthiame | | | | | | | |
| F4.1.46 | Sumatriptan | | | | | | | |
| F4.1.47 | Tiagabine | | | | | | | |
| F4.1.48 | Topiramate | | | | | | | |
| F4.1.49 | Trazodone | | | | | | | |
| F4.1.50 | Trixyphenidyl | | | | | | | |
| F4.1.51 | Tript-OH | | | | | | | |
| F4.1.52 | Valproate | | | | | | | |
| F4.1.53 | Vigabatrin | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=uneffective; 1=effective; 999= not used; SE (side effects) ; 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

TRIGGER EVENTS 1/1

(0=no; 1=yes; 888=unknown)

| | | |
|--------|-----------------------------|--|
| F5.1.1 | Stress | |
| F5.1.2 | Bathing | |
| F5.1.3 | Temperature | |
| F5.1.4 | Excitement | |
| F5.1.5 | Food | |
| F5.1.6 | Sunlight | |
| F5.1.7 | fluorescent light | |
| F5.1.8 | specific activities | |
| F5.1.9 | specific activities details | |

FURTHER INFORMATION

F6.1.0 FURTHER INFORMATION:

[Index](#)



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 1/3

| | | |
|----------------|--|--|
| F1.1.0 | TONIC OR DYSTONIC ATTACKS (0=no; 1=yes) | |
| F1.1.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.1.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 888=unknown) | |
| F1.1.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.1.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.10 | Other effective measures (0=no; 1=yes; 888=unknown) *link to the open window | |
| F1.1.11 | Trigger events (0=no; 1= yes; 888=unknown) | |

| | | |
|----------------|--|--|
| F1.2.0 | PLEGIC ATTACKS (0=no; 1=yes) | |
| F1.2.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.2.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 3= both sides; 888=unknown) | |
| F1.2.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.2.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.10 | Other effective measures (0=no; 1=yes; 888=unknown)*link to the open window | |
| F1.2.11 | Trigger events (0=no; 1= yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 2/3

| | | |
|---------------|--|--|
| F1.3.0 | ABNORMAL OCULAR MOVEMENTS (0=no; 1=yes) | |
| F1.3.1 | Semiology (0=simple; 1=complex; 888=unknown) | |
| F1.3.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.4 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.5 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.6 | Any effective drugs for acute attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.7 | Any effective prophylaxis for non epileptic attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.8 | Trigger events (0=no; 1= yes; 888=unknown) | |
| F1.3.9 | Are they linked to an other paroxysmal event? (0= no; 1= sometimes; 2=always; 888=unknown) | |
| F1.4.0 | SEIZURES (0=no; 1=yes) | |
| F1.4.1 | Semiology (0=focal, with or without secondary generalization; 1=generalized; 2=focal and generalized; 888=unknown) | |
| F1.4.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.4 | Any effective drugs for ongoing seizure ? (0=no; 1=yes; 888=unknown) | |
| F1.4.5 | Any effective drug for chronic treatment? (0=no; 1=yes;888=unknown) | |
| F1.4.6 | Is it timely linked to an other paroxysmal event? (0= no; 1= yes; 888=unknown) | |
| F1.5.0 | STATUS EPILEPTICUS (0=no; 1=yes) | |
| F1.5.1 | Semiology (0=convulsive; 1=not convulsive; 3=both; 888=unknown) | |
| F1.5.2 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.0 | HEADACHE (0=no; 1=yes) | |
| F1.6.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |
| F1.7.0 | AUTONOMIC DYSFUNCTION (0=no; 1=yes) | |
| F1.7.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.7.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 3/3

| | | |
|---------------|--|--|
| F1.8.0 | BREATHING DIFFICULTIES (0=no; 1=yes) | |
| F1.8.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.8.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.9.0 | PAIN (0=no; 1=yes) | |
| F1.9.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.9.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

COMMENTS

F1.10.0 Any significant problems in managing attacks in school?

F1.10.1 Other effective measures to treat the non-epileptic attacks?

F1.10.2 Additional information about semiology of paroxysmal events:

F1.10.3 Other Information about paroxysmal events:



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 1/2

| | | |
|----------------|--|--|
| F2.1.0 | NEUROLOGICAL DYSFUNCTION (0=no; 1=yes) | |
| F2.1.1 | Walking at home (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.2 | Walking outdoors (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.3 | Gait unsteadiness (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.4 | Gross Motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown;) | |
| F2.1.5 | Fine motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888= unknown) | |
| F2.1.6 | Pyramidal signs (0=normal; 1= increased; 2=reduced; 777= not applicable; 888=unknown) | |
| F2.1.7 | Dystonia (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.8 | Myoclonus (0= no; 1=yes, mild; 2= yes moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.9 | Chorea (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.10 | Tremor (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.11 | Complex Movement Disorder (0=no; 1=yes, mild; 2= yes moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.12 | Muscle Tone (0=normal; 1= hypertonia; 2= hypotonia; 777= not applicable; 888=unknown) | |
| F2.2.0 | MENTAL RETARDATION (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.0 | COGNITIVE DYSFUNCTION (0=no; 1=yes) | |
| F2.3.1 | Attention (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.2 | Memory (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.3 | Visuospatial (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.4 | Visuomotor (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.0 | COMMUNICATION DISORDER (0=no; 1=yes) | |
| F2.4.1 | Verbal Communication (0=no; 1=yes mild; 2= yes, moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.2 | Gestual Communication (0=no; 1=yes; 777= not applicable; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 2/2

| | | |
|---------------|---|--|
| F2.5.0 | LEARNING DISABILITIES (0=no; 1=yes) | |
| F2.5.1 | Dyslexia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.2 | Dyscalculia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.3 | Dysgraphia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |

| | | |
|---------------|---|--|
| F2.6.0 | BEHAVIOURAL DISORDERS (0=no; 1=yes; 888=unknown) | |
| F2.6.1 | Behavioural Disorders Details: | |

| | |
|---------------|------------------|
| F2.7.0 | COMMENTS: |
|---------------|------------------|



Date: _____

Patient Code provided by the center: _____

INVESTIGATIONS 1/1

| LABORATORY INVESTIGATION (0=normal; 1=not normal; 999= not done) | | | NEURORADIOLOGICAL AND NEUROPHYSIOLOGICAL INVESTIGATION (0=normal; 1=not normal; 999= not done) | | |
|---|-------------------------------|--|--|--|--|
| F3.1.1 | Base screening | | F3.2.1 | CT scan | |
| F3.1.2 | Blood Lactate | | F3.2.2 | MRI scan | |
| F3.1.3 | Blood Pyruvate | | F3.2.3 | Interictal SPECT | |
| F3.1.4 | CPK | | F3.2.4 | Ictal SPECT | |
| F3.1.5 | Blood Ammonium | | F3.2.5 | PET (*) | |
| F3.1.6 | Lysosomal enzymes | | F3.2.6 | MRI angiography | |
| F3.1.7 | Blood Amino acids | | F3.2.7 | MRI spectroscopy | |
| F3.1.8 | Blood (Urine) Organic acids | | F3.2.8 | Ictal EEG (during epileptic seizure) | |
| F3.1.9 | VLFA | | F3.2.9 | Paroxysmal EEG (during non epileptic attack) | |
| F3.1.10 | CDG | | F3.2.10 | Interictal EEG | |
| F3.1.11 | Purine, pyrimidine | | F3.2.11 | VEP | |
| F3.1.12 | Antiphospholipid | | F3.2.12 | BAEP | |
| F3.1.13 | Ana (anti nuclear antibodies) | | F3.2.13 | SEP | |
| F3.1.14 | CSF (standard examination) | | F3.2.14 | EMG | |
| F3.1.15 | CSF neurotransmitters | | F3.2.15 | ENG | |
| F3.1.16 | CSF pyruvate | | F3.2.16 | Blink reflexes | |
| F3.1.17 | CSF lactate | | F3.2.17 | ECG | |
| F3.1.18 | CSF amino acids | | F3.2.18 | Echocardiogram | |
| F3.1.19 | Muscle Biopsy | | F3.2.19 | Eye Fundus | |
| F3.1.20 | Mitochondrial chain analysis | | | (*) If "Yes" precise the tracer used : | |
| F3.1.21 | Skin Biopsy | | | | |
| F3.1.22 | Urine oligosaccharide | | | | |
| F3.1.23 | Urine mucopolysaccharide | | | | |
| F3.1.24 | Caryotype | | | | |
| F3.1.25 | Telomere analysis | | | | |

COMMENTS:

F3.3.1 Other genetic studies: (0=no; 1=yes)

F3.3.2 Other genetic studies details:

F3.4.1 Other biochemical studies: (0=no; 1=yes)

F3.4.2 Other biochemical studies details:

F3.5.1 Other instrumental investigations: (0=no; 1=yes)

F3.5.2 Other instrumental investigations details:



Date: _____

Patient Code provided by the center: _____

TREATMENT 1/2 (A - L)

| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
|---------|------------------------------|----|-----|-----|------|----|---|----|
| F4.1.1 | Acetazolamide | | | | | | | |
| F4.1.2 | Alprazolam | | | | | | | |
| F4.1.3 | Baclofen | | | | | | | |
| F4.1.4 | Barbexaclone | | | | | | | |
| F4.1.5 | Biperiden | | | | | | | |
| F4.1.6 | Bromocriptine | | | | | | | |
| F4.1.7 | Buspirone | | | | | | | |
| F4.1.8 | Carbamazepine | | | | | | | |
| F4.1.9 | Chloral Hydrate | | | | | | | |
| F4.1.10 | Cinarizine | | | | | | | |
| F4.1.11 | Ciproterone-ethinylestradiol | | | | | | | |
| F4.1.12 | Clobazam | | | | | | | |
| F4.1.13 | Clonazepam | | | | | | | |
| F4.1.14 | Clonidine | | | | | | | |
| F4.1.15 | Diazepam | | | | | | | |
| F4.1.16 | Dihydroergotamine | | | | | | | |
| F4.1.17 | Ergotamine | | | | | | | |
| F4.1.18 | Ethosuximide | | | | | | | |
| F4.1.19 | Felbamate | | | | | | | |
| F4.1.20 | Flunarizine | | | | | | | |
| F4.1.21 | Fluoxetine | | | | | | | |
| F4.1.22 | Gabapentin | | | | | | | |
| F4.1.23 | Haloperidol | | | | | | | |
| F4.1.24 | Lamotrigine | | | | | | | |
| F4.1.25 | L-dopa + carbidopa | | | | | | | |
| F4.1.26 | Levetiracetam | | | | | | | |
| F4.1.27 | Lorazepam | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=unneffective; 1=effective; 999= not used; SE (side effects); 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

TREATMENT 2/2 (M - Z)

| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
|---------|-----------------|----|-----|-----|------|----|---|----|
| F4.1.28 | Melatonin | | | | | | | |
| F4.1.29 | Metoclopramide | | | | | | | |
| F4.1.30 | Methylphenidate | | | | | | | |
| F4.1.31 | Methysergide | | | | | | | |
| F4.1.32 | Midazolam | | | | | | | |
| F4.1.33 | Niaprazine | | | | | | | |
| F4.1.34 | Nimodipine | | | | | | | |
| F4.1.35 | Nitrazepam | | | | | | | |
| F4.1.36 | Oxcarbazepine | | | | | | | |
| F4.1.37 | Phenytoin | | | | | | | |
| F4.1.38 | Phenobarbital | | | | | | | |
| F4.1.39 | Pimozide | | | | | | | |
| F4.1.40 | Piracetam | | | | | | | |
| F4.1.41 | Pregabalin | | | | | | | |
| F4.1.42 | Primidone | | | | | | | |
| F4.1.43 | Propranolol | | | | | | | |
| F4.1.44 | Sertraline | | | | | | | |
| F4.1.45 | Sulthiame | | | | | | | |
| F4.1.46 | Sumatriptan | | | | | | | |
| F4.1.47 | Tiagabine | | | | | | | |
| F4.1.48 | Topiramate | | | | | | | |
| F4.1.49 | Trazodone | | | | | | | |
| F4.1.50 | Trixyphenidyl | | | | | | | |
| F4.1.51 | Tript-OH | | | | | | | |
| F4.1.52 | Valproate | | | | | | | |
| F4.1.53 | Vigabatrin | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=unefective; 1=effective; 999= not used; SE (side effects) ; 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

TRIGGER EVENTS 1/1

(0=no; 1=yes; 888=unknown)

| | | |
|--------|-----------------------------|--|
| F5.1.1 | Stress | |
| F5.1.2 | Bathing | |
| F5.1.3 | Temperature | |
| F5.1.4 | Excitement | |
| F5.1.5 | Food | |
| F5.1.6 | Sunlight | |
| F5.1.7 | fluorescent light | |
| F5.1.8 | specific activities | |
| F5.1.9 | specific activities details | |

FURTHER INFORMATION

F6.1.0 FURTHER INFORMATION:

[Index](#)



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 1/3

| | | |
|----------------|--|--|
| F1.1.0 | TONIC OR DYSTONIC ATTACKS (0=no; 1=yes) | |
| F1.1.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.1.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 888=unknown) | |
| F1.1.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.1.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.10 | Other effective measures (0=no; 1=yes; 888=unknown) *link to the open window | |
| F1.1.11 | Trigger events (0=no; 1= yes; 888=unknown) | |

| | | |
|----------------|--|--|
| F1.2.0 | PLEGIC ATTACKS (0=no; 1=yes) | |
| F1.2.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.2.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 3= both sides; 888=unknown) | |
| F1.2.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.2.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.10 | Other effective measures (0=no; 1=yes; 888=unknown)*link to the open window | |
| F1.2.11 | Trigger events (0=no; 1= yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 2/3

| | | |
|---------------|--|--|
| F1.3.0 | ABNORMAL OCULAR MOVEMENTS (0=no; 1=yes) | |
| F1.3.1 | Semiology (0=simple; 1=complex; 888=unknown) | |
| F1.3.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.4 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.5 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.6 | Any effective drugs for acute attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.7 | Any effective prophylaxis for non epileptic attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.8 | Trigger events (0=no; 1= yes; 888=unknown) | |
| F1.3.9 | Are they linked to an other paroxysmal event? (0= no; 1= sometimes; 2=always; 888=unknown) | |
| F1.4.0 | SEIZURES (0=no; 1=yes) | |
| F1.4.1 | Semiology (0=focal, with or without secondary generalization; 1=generalized; 2=focal and generalized; 888=unknown) | |
| F1.4.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.4 | Any effective drugs for ongoing seizure ? (0=no; 1=yes; 888=unknown) | |
| F1.4.5 | Any effective drug for chronic treatment? (0=no; 1=yes;888=unknown) | |
| F1.4.6 | Is it timely linked to an other paroxysmal event? (0= no; 1= yes; 888=unknown) | |
| F1.5.0 | STATUS EPILEPTICUS (0=no; 1=yes) | |
| F1.5.1 | Semiology (0=convulsive; 1=not convulsive; 3=both; 888=unknown) | |
| F1.5.2 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.0 | HEADACHE (0=no; 1=yes) | |
| F1.6.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |
| F1.7.0 | AUTONOMIC DYSFUNCTION (0=no; 1=yes) | |
| F1.7.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.7.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 3/3

| | | |
|---------------|--|--|
| F1.8.0 | BREATHING DIFFICULTIES (0=no; 1=yes) | |
| F1.8.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.8.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.9.0 | PAIN (0=no; 1=yes) | |
| F1.9.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.9.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

COMMENTS

F1.10.0 Any significant problems in managing attacks in school?

F1.10.1 Other effective measures to treat the non-epileptic attacks?

F1.10.2 Additional information about semiology of paroxysmal events:

F1.10.3 Other Information about paroxysmal events:



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 1/2

| | | |
|----------------|--|--|
| F2.1.0 | NEUROLOGICAL DYSFUNCTION (0=no; 1=yes) | |
| F2.1.1 | Walking at home (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.2 | Walking outdoors (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.3 | Gait unsteadiness (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.4 | Gross Motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown;) | |
| F2.1.5 | Fine motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888= unknown) | |
| F2.1.6 | Pyramidal signs (0=normal; 1= increased; 2=reduced; 777= not applicable; 888=unknown) | |
| F2.1.7 | Dystonia (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.8 | Myoclonus (0= no; 1=yes, mild; 2= yes moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.9 | Chorea (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.10 | Tremor (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.11 | Complex Movement Disorder (0=no; 1=yes, mild; 2= yes moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.12 | Muscle Tone (0=normal; 1= hypertonia; 2= hypotonia; 777= not applicable; 888=unknown) | |
| F2.2.0 | MENTAL RETARDATION (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.0 | COGNITIVE DYSFUNCTION (0=no; 1=yes) | |
| F2.3.1 | Attention (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.2 | Memory (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.3 | Visuospatial (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.4 | Visuomotor (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.0 | COMMUNICATION DISORDER (0=no; 1=yes) | |
| F2.4.1 | Verbal Communication (0=no; 1=yes mild; 2= yes, moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.2 | Gestual Communication (0=no; 1=yes; 777= not applicable; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 2/2

| | | |
|---------------|---|--|
| F2.5.0 | LEARNING DISABILITIES (0=no; 1=yes) | |
| F2.5.1 | Dyslexia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.2 | Dyscalculia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.3 | Dysgraphia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |

| | | |
|---------------|---|--|
| F2.6.0 | BEHAVIOURAL DISORDERS (0=no; 1=yes; 888=unknown) | |
| F2.6.1 | Behavioural Disorders Details: | |

| | |
|---------------|------------------|
| F2.7.0 | COMMENTS: |
|---------------|------------------|



Date: _____

Patient Code provided by the center: _____

INVESTIGATIONS 1/1

| LABORATORY INVESTIGATION (0=normal; 1=not normal; 999= not done) | | |
|---|-------------------------------|--|
| F3.1.1 | Base screening | |
| F3.1.2 | Blood Lactate | |
| F3.1.3 | Blood Pyruvate | |
| F3.1.4 | CPK | |
| F3.1.5 | Blood Ammonium | |
| F3.1.6 | Lysosomal enzymes | |
| F3.1.7 | Blood Amino acids | |
| F3.1.8 | Blood (Urine) Organic acids | |
| F3.1.9 | VLFA | |
| F3.1.10 | CDG | |
| F3.1.11 | Purine, pyrimidine | |
| F3.1.12 | Antiphospholipid | |
| F3.1.13 | Ana (anti nuclear antibodies) | |
| F3.1.14 | CSF (standard examination) | |
| F3.1.15 | CSF neurotransmitters | |
| F3.1.16 | CSF pyruvate | |
| F3.1.17 | CSF lactate | |
| F3.1.18 | CSF amino acids | |
| F3.1.19 | Muscle Biopsy | |
| F3.1.20 | Mitochondrial chain analysis | |
| F3.1.21 | Skin Biopsy | |
| F3.1.22 | Urine oligosaccharide | |
| F3.1.23 | Urine mucopolysaccharide | |
| F3.1.24 | Caryotype | |
| F3.1.25 | Telomere analysis | |

| NEURORADIOLOGICAL AND NEUROPHYSIOLOGICAL INVESTIGATION (0=normal; 1=not normal; 999= not done) | | |
|--|--|--|
| F3.2.1 | CT scan | |
| F3.2.2 | MRI scan | |
| F3.2.3 | Interictal SPECT | |
| F3.2.4 | Ictal SPECT | |
| F3.2.5 | PET (*) | |
| F3.2.6 | MRI angiography | |
| F3.2.7 | MRI spectroscopy | |
| F3.2.8 | Ictal EEG (during epileptic seizure) | |
| F3.2.9 | Paroxysmal EEG (during non epileptic attack) | |
| F3.2.10 | Interictal EEG | |
| F3.2.11 | VEP | |
| F3.2.12 | BAEP | |
| F3.2.13 | SEP | |
| F3.2.14 | EMG | |
| F3.2.15 | ENG | |
| F3.2.16 | Blink reflexes | |
| F3.2.17 | ECG | |
| F3.2.18 | Echocardiogram | |
| F3.2.19 | Eye Fundus | |
| | (*) If "Yes" precise the tracer used : | |
| | | |

COMMENTS:

F3.3.1 Other genetic studies: (0=no; 1=yes)

F3.3.2 Other genetic studies details:

F3.4.1 Other biochemical studies: (0=no; 1=yes)

F3.4.2 Other biochemical studies details:

F3.5.1 Other instrumental investigations: (0=no; 1=yes)

F3.5.2 Other instrumental investigations details:



Date: _____

Patient Code provided by the center: _____

TREATMENT 1/2 (A - L)

| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
|---------|------------------------------|----|-----|-----|------|----|---|----|
| F4.1.1 | Acetazolamide | | | | | | | |
| F4.1.2 | Alprazolam | | | | | | | |
| F4.1.3 | Baclofen | | | | | | | |
| F4.1.4 | Barbexaclone | | | | | | | |
| F4.1.5 | Biperiden | | | | | | | |
| F4.1.6 | Bromocriptine | | | | | | | |
| F4.1.7 | Buspirone | | | | | | | |
| F4.1.8 | Carbamazepine | | | | | | | |
| F4.1.9 | Chloral Hydrate | | | | | | | |
| F4.1.10 | Cinarizine | | | | | | | |
| F4.1.11 | Ciproterone-ethinylestradiol | | | | | | | |
| F4.1.12 | Clobazam | | | | | | | |
| F4.1.13 | Clonazepam | | | | | | | |
| F4.1.14 | Clonidine | | | | | | | |
| F4.1.15 | Diazepam | | | | | | | |
| F4.1.16 | Dihydroergotamine | | | | | | | |
| F4.1.17 | Ergotamine | | | | | | | |
| F4.1.18 | Ethosuximide | | | | | | | |
| F4.1.19 | Felbamate | | | | | | | |
| F4.1.20 | Flunarizine | | | | | | | |
| F4.1.21 | Fluoxetine | | | | | | | |
| F4.1.22 | Gabapentin | | | | | | | |
| F4.1.23 | Haloperidol | | | | | | | |
| F4.1.24 | Lamotrigine | | | | | | | |
| F4.1.25 | L-dopa + carbidopa | | | | | | | |
| F4.1.26 | Levetiracetam | | | | | | | |
| F4.1.27 | Lorazepam | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=uneffective; 1=effective; 999= not used; SE (side effects); 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

| TREATMENT 2/2 (M - Z) | | | | | | | | |
|-----------------------|-----------------|----|-----|-----|------|----|---|----|
| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
| F4.1.28 | Melatonin | | | | | | | |
| F4.1.29 | Metoclopramide | | | | | | | |
| F4.1.30 | Methylphenidate | | | | | | | |
| F4.1.31 | Methysergide | | | | | | | |
| F4.1.32 | Midazolam | | | | | | | |
| F4.1.33 | Niaprazine | | | | | | | |
| F4.1.34 | Nimodipine | | | | | | | |
| F4.1.35 | Nitrazepam | | | | | | | |
| F4.1.36 | Oxcarbazepine | | | | | | | |
| F4.1.37 | Phenytoin | | | | | | | |
| F4.1.38 | Phenobarbital | | | | | | | |
| F4.1.39 | Pimozide | | | | | | | |
| F4.1.40 | Piracetam | | | | | | | |
| F4.1.41 | Pregabalin | | | | | | | |
| F4.1.42 | Primidone | | | | | | | |
| F4.1.43 | Propranolol | | | | | | | |
| F4.1.44 | Sertraline | | | | | | | |
| F4.1.45 | Sulthiame | | | | | | | |
| F4.1.46 | Sumatriptan | | | | | | | |
| F4.1.47 | Tiagabine | | | | | | | |
| F4.1.48 | Topiramate | | | | | | | |
| F4.1.49 | Trazodone | | | | | | | |
| F4.1.50 | Trixyphenidyl | | | | | | | |
| F4.1.51 | Tript-OH | | | | | | | |
| F4.1.52 | Valproate | | | | | | | |
| F4.1.53 | Vigabatrin | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=unneffective; 1=effective; 999= not used; SE (side effects) ; 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

TRIGGER EVENTS 1/1

(0=no; 1=yes; 888=unknown)

| | | |
|--------|-----------------------------|--|
| F5.1.1 | Stress | |
| F5.1.2 | Bathing | |
| F5.1.3 | Temperature | |
| F5.1.4 | Excitement | |
| F5.1.5 | Food | |
| F5.1.6 | Sunlight | |
| F5.1.7 | fluorescent light | |
| F5.1.8 | specific activities | |
| F5.1.9 | specific activities details | |

FURTHER INFORMATION

F6.1.0 FURTHER INFORMATION:

[Index](#)



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 1/3

| | | |
|----------------|--|--|
| F1.1.0 | TONIC OR DYSTONIC ATTACKS (0=no; 1=yes) | |
| F1.1.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.1.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 888=unknown) | |
| F1.1.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.1.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.1.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.1.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.1.10 | Other effective measures (0=no; 1=yes; 888=unknown) *link to the open window | |
| F1.1.11 | Trigger events (0=no; 1= yes; 888=unknown) | |

| | | |
|----------------|--|--|
| F1.2.0 | PLEGIC ATTACKS (0=no; 1=yes) | |
| F1.2.1 | Semiology (0=simple; 1= mixed; 888=unknown) | |
| F1.2.2 | Limb involvement (0=one; 1= >1 same side; 2= >1 different side; 3= both sides; 888=unknown) | |
| F1.2.3 | Impairment of Consciousness (0= no; 1=yes, seldom; 2=yes, frequent/always; 888=unknown) | |
| F1.2.4 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.5 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.2.6 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.7 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.2.8 | Any effective drugs for acute attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.9 | Any effective prophylaxis for non epileptic attacks? (0=no; 1=yes; 888=unknown) | |
| F1.2.10 | Other effective measures (0=no; 1=yes; 888=unknown)*link to the open window | |
| F1.2.11 | Trigger events (0=no; 1= yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 2/3

| | | |
|---------------|--|--|
| F1.3.0 | ABNORMAL OCULAR MOVEMENTS (0=no; 1=yes) | |
| F1.3.1 | Semiology (0=simple; 1=complex; 888=unknown) | |
| F1.3.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.3.4 | Length without treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.5 | Length with treatment or drug (0=<1hour; 1=1-6 hours; 2=6-12 hours; 3=12-24 hours, 4=>24 hours; 888=unknown) | |
| F1.3.6 | Any effective drugs for acute attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.7 | Any effective prophylaxis for non epileptic attack? (0=no; 1=yes; 888=unknown) | |
| F1.3.8 | Trigger events (0=no; 1= yes; 888=unknown) | |
| F1.3.9 | Are they linked to an other paroxysmal event? (0= no; 1= sometimes; 2=always; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.4.0 | SEIZURES (0=no; 1=yes) | |
| F1.4.1 | Semiology (0=focal, with or without secondary generalization; 1=generalized; 2=focal and generalized; 888=unknown) | |
| F1.3.2 | Frequency without treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.3 | Frequency with treatment or drug (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.4.4 | Any effective drugs for ongoing seizure ? (0=no; 1=yes; 888=unknown) | |
| F1.4.5 | Any effective drug for chronic treatment? (0=no; 1=yes;888=unknown) | |
| F1.4.6 | Is it timely linked to an other paroxysmal event? (0= no; 1= yes; 2=always; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.5.0 | STATUS EPILEPTICUS (0=no; 1=yes) | |
| F1.5.1 | Semiology (0=convulsive; 1=not convulsive; 3=both; 888=unknown) | |
| F1.5.2 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.6.0 | HEADACHE (0=no; 1=yes) | |
| F1.6.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.6.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.7.0 | AUTONOMIC DYSFUNCTION (0=no; 1=yes) | |
| F1.7.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.7.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

PAROXYSMAL EVENTS 3/3

| | | |
|---------------|--|--|
| F1.8.0 | BREATHING DIFFICULTIES (0=no; 1=yes) | |
| F1.8.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.8.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

| | | |
|---------------|--|--|
| F1.9.0 | PAIN (0=no; 1=yes) | |
| F1.9.1 | Frequency (0=<1/year; 1=1-6/year; 2=monthly; 3=weekly; 4=daily; 888=unknown) | |
| F1.9.2 | Is it linked to other paroxysmal event? (0=no; 1=yes; 888=unknown) | |

COMMENTS

F1.10.0 Any significant problems in managing attacks in school?

F1.10.1 Other effective measures to treat the non-epileptic attacks?

F1.10.2 Additional information about semiology of paroxysmal events:

F1.10.3 Other Information about paroxysmal events:



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 1/2

| | | |
|---------|--|--|
| F2.1.0 | NEUROLOGICAL DYSFUNCTION (0=no; 1=yes) | |
| F2.1.1 | Walking at home (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.2 | Walking outdoors (0= autonomous; 1= with help; 2= not possible; 777= not applicable; 888=unknown) | |
| F2.1.3 | Gait unsteadiness (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.4 | Gross Motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown;) | |
| F2.1.5 | Fine motor problems (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888= unknown) | |
| F2.1.6 | Pyramidal signs (0=normal; 1= increased; 2=reduced; 777= not applicable; 888=unknown) | |
| F2.1.7 | Dystonia (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.8 | Myoclonus (0= no; 1=yes, mild; 2= yes moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.9 | Chorea (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.10 | Tremor (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.11 | Complex Movement Disorder (0=no; 1=yes, mild; 2= yes moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.1.12 | Muscle Tone (0=normal; 1= hypertonia; 2= hypotonia; 777= not applicable; 888=unknown) | |
| F2.2.0 | MENTAL RETARDATION (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.0 | COGNITIVE DYSFUNCTION (0=no; 1=yes) | |
| F2.3.1 | Attention (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.2 | Memory (0=no; 1=yes, mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.3 | Visuospatial (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.3.4 | Visuomotor (0=no; 1=yes mild; 2= yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.0 | COMMUNICATION DISORDER (0=no; 1=yes) | |
| F2.4.1 | Verbal Communication (0=no; 1=yes mild; 2= yes, moderate; 3= yes, severe; 777= not applicable; 888=unknown) | |
| F2.4.2 | Gestual Communication (0=no; 1=yes; 777= not applicable; 888=unknown) | |



Date: _____

Patient Code provided by the center: _____

NON PAROXYSMAL FEATURES 2/2

| | | |
|---------------|---|--|
| F2.5.0 | LEARNING DISABILITIES (0=no; 1=yes) | |
| F2.5.1 | Dyslexia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.2 | Dyscalculia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |
| F2.5.3 | Dysgraphia (0=no; 1=yes, mild; 2=yes, moderate; 3=yes, severe; 777= not applicable; 888=unknown) | |

| | | |
|---------------|---|--|
| F2.6.0 | BEHAVIOURAL DISORDERS (0=no; 1=yes; 888=unknown) | |
| F2.6.1 | Behavioural Disorders Details: | |

| | |
|---------------|------------------|
| F2.7.0 | COMMENTS: |
|---------------|------------------|



Date: _____

Patient Code provided by the center: _____

INVESTIGATIONS 1/1

| LABORATORY INVESTIGATION (0=normal; 1=not normal; 999= not done) | | | NEURORADIOLOGICAL AND NEUROPHYSIOLOGICAL INVESTIGATION (0=normal; 1=not normal; 999= not done) | | |
|---|-------------------------------|--|--|--|--|
| F3.1.1 | Base screening | | F3.2.1 | CT scan | |
| F3.1.2 | Blood Lactate | | F3.2.2 | MRI scan | |
| F3.1.3 | Blood Pyruvate | | F3.2.3 | Interictal SPECT | |
| F3.1.4 | CPK | | F3.2.4 | Ictal SPECT | |
| F3.1.5 | Blood Ammonium | | F3.2.5 | PET (*) | |
| F3.1.6 | Lysosomal enzymes | | F3.2.6 | MRI angiography | |
| F3.1.7 | Blood Amino acids | | F3.2.7 | MRI spectroscopy | |
| F3.1.8 | Blood (Urine) Organic acids | | F3.2.8 | Ictal EEG (during epileptic seizure) | |
| F3.1.9 | VLFA | | F3.2.9 | Paroxysmal EEG (during non epileptic attack) | |
| F3.1.10 | CDG | | F3.2.10 | Interictal EEG | |
| F3.1.11 | Purine, pyrimidine | | F3.2.11 | VEP | |
| F3.1.12 | Antiphospholipid | | F3.2.12 | BAEP | |
| F3.1.13 | Ana (anti nuclear antibodies) | | F3.2.13 | SEP | |
| F3.1.14 | CSF (standard examination) | | F3.2.14 | EMG | |
| F3.1.15 | CSF neurotransmitters | | F3.2.15 | ENG | |
| F3.1.16 | CSF pyruvate | | F3.2.16 | Blink reflexes | |
| F3.1.17 | CSF lactate | | F3.2.17 | ECG | |
| F3.1.18 | CSF amino acids | | F3.2.18 | Echocardiogram | |
| F3.1.19 | Muscle Biopsy | | F3.2.19 | Eye Fundus | |
| F3.1.20 | Mitochondrial chain analysis | | | (*) If "Yes" precise the tracer used : | |
| F3.1.21 | Skin Biopsy | | | | |
| F3.1.22 | Urine oligosaccharide | | | | |
| F3.1.23 | Urine mucopolysaccharide | | | | |
| F3.1.24 | Caryotype | | | | |
| F3.1.25 | Telomere analysis | | | | |

COMMENTS:

F3.3.1 Other genetic studies: (0=no; 1=yes)

F3.3.2 Other genetic studies details:

F3.4.1 Other biochemical studies: (0=no; 1=yes)

F3.4.2 Other biochemical studies details:

F3.5.1 Other instrumental investigations: (0=no; 1=yes)

F3.5.2 Other instrumental investigations details:



Date: _____

Patient Code provided by the center: _____

TREATMENT 1/2 (A - L)

| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
|---------|------------------------------|----|-----|-----|------|----|---|----|
| F4.1.1 | Acetazolamide | | | | | | | |
| F4.1.2 | Alprazolam | | | | | | | |
| F4.1.3 | Baclofen | | | | | | | |
| F4.1.4 | Barbexaclone | | | | | | | |
| F4.1.5 | Biperiden | | | | | | | |
| F4.1.6 | Bromocriptine | | | | | | | |
| F4.1.7 | Buspirone | | | | | | | |
| F4.1.8 | Carbamazepine | | | | | | | |
| F4.1.9 | Chloral Hydrate | | | | | | | |
| F4.1.10 | Cinarizine | | | | | | | |
| F4.1.11 | Ciproterone-ethinylestradiol | | | | | | | |
| F4.1.12 | Clobazam | | | | | | | |
| F4.1.13 | Clonazepam | | | | | | | |
| F4.1.14 | Clonidine | | | | | | | |
| F4.1.15 | Diazepam | | | | | | | |
| F4.1.16 | Dihydroergotamine | | | | | | | |
| F4.1.17 | Ergotamine | | | | | | | |
| F4.1.18 | Ethosuximide | | | | | | | |
| F4.1.19 | Felbamate | | | | | | | |
| F4.1.20 | Flunarizine | | | | | | | |
| F4.1.21 | Fluoxetine | | | | | | | |
| F4.1.22 | Gabapentin | | | | | | | |
| F4.1.23 | Haloperidol | | | | | | | |
| F4.1.24 | Lamotrigine | | | | | | | |
| F4.1.25 | L-dopa + carbidopa | | | | | | | |
| F4.1.26 | Levetiracetam | | | | | | | |
| F4.1.27 | Lorazepam | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=uneffective; 1=effective; 999= not used; SE (side effects) ; 0=no; 1=yes; 888=unknown



Date: _____

Patient Code provided by the center: _____

| TREATMENT 1/2 (A - L) | | | | | | | | |
|-----------------------|-----------------|----|-----|-----|------|----|---|----|
| | DRUGS | PE | PNE | ATE | ATNE | SI | P | SE |
| F4.1.28 | Melatonin | | | | | | | |
| F4.1.29 | Metoclopramide | | | | | | | |
| F4.1.30 | Methylphenidate | | | | | | | |
| F4.1.31 | Methysergide | | | | | | | |
| F4.1.32 | Midazolam | | | | | | | |
| F4.1.33 | Niaprazine | | | | | | | |
| F4.1.34 | Nimodipine | | | | | | | |
| F4.1.35 | Nitrazepam | | | | | | | |
| F4.1.36 | Oxcarbazepine | | | | | | | |
| F4.1.37 | Phenytoin | | | | | | | |
| F4.1.38 | Phenobarbital | | | | | | | |
| F4.1.39 | Pimozide | | | | | | | |
| F4.1.40 | Piracetam | | | | | | | |
| F4.1.41 | Pregabalin | | | | | | | |
| F4.1.42 | Primidone | | | | | | | |
| F4.1.43 | Propranolol | | | | | | | |
| F4.1.44 | Sertraline | | | | | | | |
| F4.1.45 | Sulthiame | | | | | | | |
| F4.1.46 | Sumatriptan | | | | | | | |
| F4.1.47 | Tiagabine | | | | | | | |
| F4.1.48 | Topiramate | | | | | | | |
| F4.1.49 | Trazodone | | | | | | | |
| F4.1.50 | Trixyphenidyl | | | | | | | |
| F4.1.51 | Tript-OH | | | | | | | |
| F4.1.52 | Valproate | | | | | | | |
| F4.1.53 | Vigabatrin | | | | | | | |

Legende: PE(prophylaxis for Epilepsy); PNE (Prophylaxis for non Epileptic attacks); ATE (acute treatment in epileptic attack); ATNE (acute treatment in non-epileptic attack); SI (sleep induction); P (pain); 0=unneffective; 1=effective; 999= not used; SE (side effects); 0=no; 1=yes; 888=unknown



Date: _____

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TRIGGER EVENTS 1/1

(0=no; 1=yes; 888=unknown)

| | | |
|--------|-----------------------------|--|
| F5.1.1 | Stress | |
| F5.1.2 | Bathing | |
| F5.1.3 | Temperature | |
| F5.1.4 | Excitement | |
| F5.1.5 | Food | |
| F5.1.6 | Sunlight | |
| F5.1.7 | fluorescent light | |
| F5.1.8 | specific activities | |
| F5.1.9 | specific activities details | |

FURTHER INFORMATION

F6.1.0 FURTHER INFORMATION:

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