



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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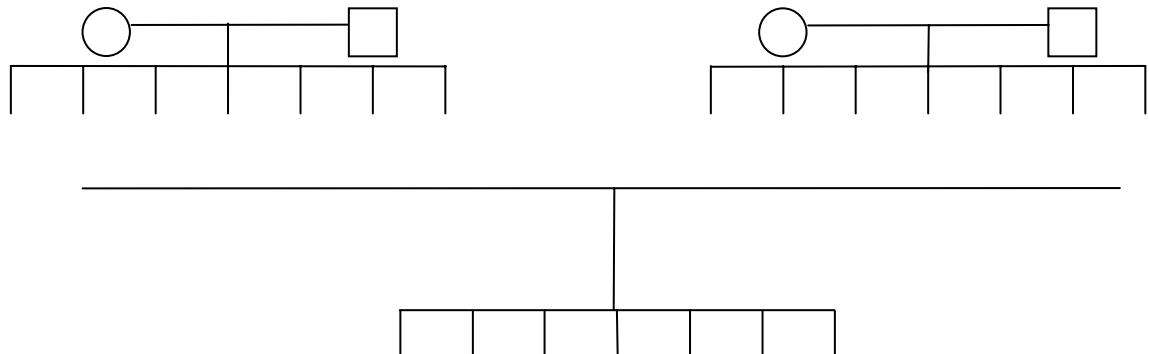
Treating Physician

Patient Code Provided by the Center

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:

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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: _____

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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: _____

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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:
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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: _____

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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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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:
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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:
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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=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:

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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:
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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)	



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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)	



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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:
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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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