Deliverable

D8.1 Directory of current recruiting research studies

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Workpackage: 8

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Current recruiting clinical studies in ERN-RND

1) National studies

Brief Title	Official Title	ERN-RND Disease Group	Contact person for study	Study/Trial
Biomarkers in Parkinsonian Syndromes	Development of Biomarkers for the Diagnosis and Prognosis of Parkinsonian Syndromes Running Head: Biomarkers in Parkinsonian Syndromes	Atypical parkinsonian syndromes	sandrine.villars@chu-bordeaux.fr	Clinical study
COPPADIS-2015	Cohort of Patients with Parkinson's Disease in Spain 2015: A global Parkinson´s disease project underway	Atypical parkinsonian syndromes	ycompta@clinic.cat	Clinical study
Differential diagnosis between Parkinson's disease and Multiple System Atrophy using digital speech analysis - Voice4PD-MSA	Differential diagnosis between Parkinson's disease and Multiple System Atrophy using digital speech analysis - Voice4PD-MSA	Atypical parkinsonian syndromes	Sandrine.villars@chu-bordeaux.fr	Clinical study
DROXI DOPA on OH in MSA patients	Long-term effects of L-ThreoDOPS (3 months) on orthostatic hypotension and other non motor symptoms in Multiple System Atrophy : randomized clinical trial versus placebo	Atypical parkinsonian syndromes	nadege.kouassi@inserm.fr	Trial
HYPOSOMN PARK	Post-prandial hypotension and sleepiness in Parkinson's disease and other synucleinopathies: the model of an oral glucose load	Atypical parkinsonian syndromes	pavy-letraon.a@chu-toulouse.fr	Clinical study
Oligomeric alpha-synuclein in multiple system atrophy	Oligomeric alpha-synuclein levels as a biomarker for multiple system atrophy	Atypical parkinsonian syndromes	sandrine.dupouy@chu-bordeaux.fr	Clinical study
Study Assessing Safety and Therapeutic Activity of AFFITOPE® PD01A and PD03A in Patients With Early MSA	A Randomized, Placebo-controlled, Parallel Group, Patient-blind, Phase I Study Assessing the Safety and Exploring the Immunogenicity/Therapeutic Activity of AFFITOPE® PD01A and PD03A in Patients With Early Multiple System Atrophy	Atypical parkinsonian syndromes	sandrine.villars@chu-bordeaux.fr	Trial
UROPARKTENS	Evaluation of treatment by transcutaneous electrical nerve stimulation (TENS) of the posterior tibial nerve for lower urinary tract disorders in Parkinson's syndrome	Atypical parkinsonian syndromes	bonnet.sandrine@chu-toulouse.fr	Trial
ATRIL	MULTICENTER, RANDOMIZED, DOUBLE BLIND, PLACEBO CONTROLLED CLINICAL TRIAL WITH RILUZOLE IN	Cerebellar Ataxias and Spastic Paraplegias	elodie.petit@icm-institute.org	Trial

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	SPINOCEREBELLAR ATAXIA TYPE 2			
BIOSCA	Biomarkers in Autosomal Dominant Cerebellar Ataxia	Cerebellar Ataxias and Spastic Paraplegias	elodie.petit@icm-institute.org	Clinical study
CARFA	A Study to Characterize the Cardiac Phenotype of Individuals with Friedreich's Ataxia	Cerebellar Ataxias and Spastic Paraplegias	lynda.benammar@icm-institute.org	Clinical study
Expand-survey	EXPeriences And NeeDs of patients with hereditary spastic paraplegia (Expand)	Cerebellar Ataxias and Spastic Paraplegias	bas.vanlith@radboudumc.nl	Clinical study
Feboch-II	Functional Effects of BOtulinum toxin treatment and subsequent stretChing of spastic hip adductors in Hereditary spastic paraplegia	Cerebellar Ataxias and Spastic Paraplegias	bas.vanlith@radboudumc.nl	Clinical study
MODIFSPA	Identification of genetic, epigenetic and environmental modifiers in hereditary spastic paraplegia	Cerebellar Ataxias and Spastic Paraplegias	lynda.benammar@icm-institute.org	Clinical study
ORFA	Longitudinal analysis of oral communication in Friedreich's ataxia	Cerebellar Ataxias and Spastic Paraplegias	lynda.benammar@icm-institute.org	Clinical study
Preclinical SCA3	Cerebral changes and compensation in preclinical SCA3	Cerebellar Ataxias and Spastic Paraplegias	bart.vandewarrenburg@radboudumc.nl	Clinical study
RF-2011-02347420	Monitoring disease progression and phenotypic heterogeneity in hereditary ataxias	Cerebellar Ataxias and Spastic Paraplegias	caterina.mariotti@istituto-besta.it	Clinical study
RISCA	Prospective Study of Individuals at Risk for Spinocerebellar Ataxia Type 1, Type 2, Type 3, Type 6 and Type 7 (SCA1, SCA2, SCA3, SCA6, SCA	Cerebellar Ataxias and Spastic Paraplegias	lynda.benammar@icm-institute.org	Clinical study
SPA-M	Therapeutic Metabolic Intervention in Patients With Spastic Paraplegia SPG5	Cerebellar Ataxias and Spastic Paraplegias	elodie.petit@icm-institute.org	Trial
Training in SCA	Understanding and manipulating compensatory mechanisms in spinocerebellar ataxia	Cerebellar Ataxias and Spastic Paraplegias	bart.vandewarrenburg@radboudumc.nl	Clinical study
Danse-HD	Evaluation of the effects of contemporary dance practice on the behaviour and the brain in HD patients	Choreas and Huntington's Disease	elodie.petit@icm-institute.org	Clinical study
DEVPolyQ	Embryonic development of the cortex in human embryos with pathological expansions of polyglutamines	Choreas and Huntington's Disease	lynda.benammar@icm-institute.org	Clinical study

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HD-Biomarkers	Identification of biomarkers that can be used to track the progression of Huntington's Disease (HD)	Choreas and Huntington's Disease	m.lewis@ucl.ac.uk	Clinical study
HD-YAS	Huntington's Disease Young Adult Study	Choreas and Huntington's Disease	m.lewis@ucl.ac.uk	Clinical study
IONIS-HTTRx CS1	A Randomized, Double-blind, Placebo-controlled Study to Evaluate the Safety, Tolerability, Pharmacokinetics and Pharmacodynamics of Multiple Ascending Doses of Intrathecally Administered ISIS 443139 in Patients With Early Manifest Huntington's Disease	Choreas and Huntington's Disease	m.lewis@ucl.ac.uk	Trial
LEGATO-HD	A Multicenter, Multinational, Randomized, Double-Blind, Placebo-Controlled, Parallel-Group Study to Evaluate the Efficacy and Safety of Laquinimod (0.5, 1.0 and 1.5 mg/day) as Treatment in Patients with Huntington's Disease	Choreas and Huntington's Disease	m.lewis@ucl.ac.uk	Trial
LEGATO-HD	Laquinimod Efficacy and Safety in a GlobAl Trial Of HD (Study TV5600-CNS-20007)	Choreas and Huntington's Disease	ycompta@clinic.cat	Clinical study
NEUROHD	Neuroleptic and Huntington Disease. Comparison of : Olanzapine, la Tetrabenazine and Tiapride. A Multicentric, Randomised, Controlled Study.	Choreas and Huntington's Disease	elodie.petit@icm-institute.org	Trial
RISQUINFO	Are prenatal and pre-implantation diagnoses an issue for family information?	Choreas and Huntington's Disease	elodie.petit@icm-institute.org	Clinical study
WIN-HD	Decoding Presymptomatic White Matter Changes in Huntington Disease	Choreas and Huntington's Disease	elodie.petit@icm-institute.org	Clinical study
AGENT10	Agentivity in Dystonia	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	yulia.worbe@aphp.fr	Clinical study

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Agent10	Agentivity in dystonia	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	Yulia.worbe@aphp.fr	Clinical study
AMEDYST	Alterations of Motor nEtworks in primary DYSTonia	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	emmanuel.roze@aphp.fr	Clinical study
Dystonic tremor	The cerebral mechanisms underlying dystonic and essential tremor: a multimodal network approach	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	Rick Helmich (rick.helmich@radboudumc.nl)	Clinical study
Spidy Follow-up	pallidal stimulation in dystonia : 10 years follow-up	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	marie.vidailhet@aphp.fr	Clinical study
ECOCAPTURE	Assessment of Apathy in a Real-life Situation, With a Video and Sensors-based System in Healthy Subject and Patient With Cerebral Disease	Frontotemporal dementia	Richard Levy richard.levy@aphp.fr	Clinical study
FTD-RisC	Early biomarker abnormalities in patients with frontotemporal dementia	Frontotemporal dementia	Jessica Panman - j.panman@erasmusmc.nl	Clinical study
FTLD-exome	Identification of new genes causing frontotemporal lobar degeneration by whole exome sequencing and characterization of the associated phenotypes	Frontotemporal dementia	isabelle.leber@upmc.fr	Clinical study
PREDICT-PGRN	Characterization and natural history of symptomatic and asymptomatic patients with PGRN mutation	Frontotemporal dementia	isabelle.leber@upmc.fr	Clinical study
PREV DemAls	Prédire pour prévenir les démences frontotemporales (DFT) et la sclérose latérale amyotrophique (SLA)	Frontotemporal dementia	isabelle.leber@upmc.fr	Clinical study
PREV-DemAls	Predict to Prevent Frontotemporal Lobar Degeneration (FDT) and Amyotrophic Lateral Sclerosis (ALS)	Frontotemporal dementia	isabelle.leber@upmc.fr	Clinical study

Brief Title	Official Title	ERN-RND Disease Group	Contact person for study	Study/Trial
RBM 02-59	Clinical and Genetic Study of Neurodegenerative Disorders With Cognitive Impairment	Frontotemporal dementia	Alexis Brice alexis.brice@icm-institute.org	Clinical study

2) International studies

Brief Title	Official Title	ERN-RND Disease Group	Contact person for study	Study/Trial
EPIPARK	Epidemiology of Nonmotor-Symptoms in PD	Atypical parkinsonian syndromes	barbara.staemmler@neuro.uni-luebeck.de	Clinical study
MitoPD	An omics-based strategy using coenzyme Q10 in patients with Parkinson's disease: Concept evaluation in a double-blind randomized placebo-controlled parallel group trial	Atypical parkinsonian syndromes	jannik.prasuhn@neuro.uni-luebeck.de	Trial
SYSMED-PD	Systems Medicine of Mitochondrial Parkinson's Disease	Atypical parkinsonian syndromes	sysmedpd@neuro.uni-luebeck.de	Clinical study
ALCAT	Effects of acetyl-DL-leucine on cerebellar ataxia - a multinational, multicenter, randomized, double-blind, placebo-controlled, 2-way crossover phase III trial	Cerebellar Ataxias and Spastic Paraplegias	klockgether@uni-Bonn.de	Clinical study
AOA1 study	Evolution of Albumin on AOA1 Patients Supplemented With Coenzyme Q10	Cerebellar Ataxias and Spastic Paraplegias	elodie.petit@icm-institute.org	Trial
EFACTS	Patient Registry of the European Friedreich's Ataxia Consortium for Translational Studies	Cerebellar Ataxias and Spastic Paraplegias	lynda.benammar@icm-institute.org	Clinical study
EFACTS	European Friedreich's Ataxia Consortium for Translational Studies	Cerebellar Ataxias and Spastic Paraplegias	lorenzo.nanetti@istituto-besta.it; anna.castaldo@istituto-besta.it	Clinical study
Legato	Lagato	Choreas and Huntington's Disease	jiri.klempir@seznam.cz	Clinical study
LEGATO-HD	A Multicenter, Multinational, Randomized,	Choreas and Huntington's	jemunoz@clinic.ub.es	Trial

Brief Title	Official Title	ERN-RND Disease Group	Contact person for study	Study/Trial
	Double-Blind, Placebo-Controlled, Parallel-Group Study to Evaluate the Efficacy and Safety of Laquinimod (0.5, 1.0 and 1.5 mg/day) as Treatment in Patients with Huntington's Disease	Disease		
LEGATO-HD	A multicenter, randomized, double-blind, placebo-controlled, parallel-group study to evaluate the efficacy and safety of Laquinimod (0.5, 1 mg/day) as treatment in patients with Huntington disease.	Choreas and Huntington's Disease	lorenzo.nanetti@istituto-besta.it; anna.castaldo@istituto-besta.it	Trial
AMEDYST	Alterations of Motor nEtworks in primary DYSTonia	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	emmanuel.roze@aphp.fr	Clinical study
Non-motor symptoms of dystonia	Non-motor symptoms of dystonia	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	kovacs.norbert@pte.hu	Clinical study
i.th. enzymereplacement in MLD	HGT MLD 070 study HGT MLD 071 follow-up study	Frontotemporal dementia	annette.hark@med.uni-tuebingen.de	Clinical study
Rhapsody WP5 pilot study	Rhapsody WP5 Feasibility study of online program for family caregivers	Frontotemporal dementia	im2aanna@gmail.com	Trial
ALD-102	A Phase 2/3 Study of the Efficacy and Safety of Hematopoietic Stem Cells Transduced With Lenti-D Lentiviral Vector for the Treatment of Cerebral Adrenoleukodystrophy (CALD)	Leukodystrophies	patrick.aubourg@inserm.fr; caroline.sevin@inserm.fr	Trial
C1109	A phase I/II, Open Labeled, Monocentric Study of Direct Intracranial Administration of a Replication Deficient Adeno-associated Virus Gene Transfer Vector Serotype rh.10 Expressing the Human ARSA cDNA to Children with Metachromatic Leukodystrophy	Leukodystrophies	caroline.sevin@inserm.fr	Trial
HGT-MLD-071	An Open-Label Extension of Study HGT-MLD-070 Evaluating Long Term Safety and Efficacy	Leukodystrophies	caroline.sevin@inserm.fr	Trial

Brief Title	Official Title	ERN-RND Disease Group	Contact person for study	Study/Trial
	of Intrathecal Administration of HGT-1110 in Patients with Metachromatic Leukodystrophy			
MIN-102	A RANDOMIZED, DOUBLE-BLIND, PLACEBO-CONTROLLED, MULTINATIONAL, MULTICENTER STUDY WITH OPEN-LABEL TREATMENT EXTENSION TO ASSESS THE EFFECT OF MIN-102 ON THE PROGRESSION OF ADRENOMYELONEUROPATHY IN MALE PATIENTS WITH X-LINKED ADRENOLEUKODYSTROPHY	Leukodystrophies	josepgamez.bcn@gmail.com	Clinical study
Natural history of leukodystrophies	Natural history of selected leukodystrophies	Leukodystrophies	n.wolf@vumc.nl	Clinical study
Enroll-HD	A Prospective Registry Study in a Global Huntington's Disease Cohort		lorenzo.nanettiistituto-besta.it; anna.castaldo@istituto-besta.it	Clinical study