NRC-RPD Consortium
National Reference Center rare disease [NRC] for (rapidly) progressive dementia's [RPD] for diagnosing Creutzfeldt-Jakob disease (ddCJD)

Labo Neuro I IBB-Neurobiobank
Instituut Born-Bunge vzw
Universiteit Antwerpen
biomarkers@uantwerpen.be

Universiteitsplein 1 D.T630
2610 Antwerpen - België
www.uantwerpen.be/sampling
Tel: +32 3 265 26 05

Labo Klinische Biologie
Drie Eikenstraat 655
2560 Edegem
Erk.nr. 8-11603-93-998

Biological markers for neurodegeneration in Cerebrospinal Fluid (CSF) samples

To the attention of the patient or his representative:

Dear Madam, Dear Sir,

*There is **no analysis cost for markers of Creutzfeldt-Jacob disease** (ddCJD). **Analyses with markers of Alzheimer's disease** (ddAD) **are not reimbursed** by the Belgian Belgian health insurance (RIZIV/INAMI). **You will be charged for this analysis cost via your hospital invoice.** However, some supplementary hospitalisation insurances intervene in this analysis cost.*

☐ **I have been informed about the cost of the analyses: analysis cost ddCJD: € 0 / analysis cost ddAD: € 125**

The Born Bunge Institute (IBB, www.uantwerpen.be/ibb-neurobiobank) located at the University of Antwerp, wishes to use, after analyzing your bodily fluid sample, the residual volume for further scientific research. Your residual CSF sample will be stored in the IBB Biobank. Your personal data as well as the clinical findings as provided below by your attending physician will be pseudonymized and will be kept in a safely manner. The link with your doctor and the hospital will remain intact as well.

To accelerate scientific research into the diagnosis of these neurodegenerative disorders we would like to ask without obligation to provide a blood sample (plasma sample) in addition to your CSF sample. This appended plasma sample will be stored in the IBB Biobank in a similar way as your CSF sample (www.uantwerpen.be/sampling). Scientists can then appeal to it.

If you wish to object to the use of this residual bodily fluid sample(s) for further scientific biomarker research, please do state so to your doctor who will note this on the form. In case of incidental findings with importance for your health, you will be informed.

☐ **I have been informed about the scientific added value of pseudonymised storage and further use of my CSF/plasma samples.**
I retain the right to access and correct my data, cfr. https://www.uantwerpen.be/privacybeleid

Date: _____ Date and signature patient or his representative: _____

To the attention of the doctor:

Sample receipt: Labo klinische biologie UZA, route 169
Drie Eikenstraat 655
2650 Edegem
Dr. Khadija Guerti (riziv nr. 11943866860)

Analysis / interpretation: Labo Neuro/Neurobiobank IBB-UA
E-mail: biomarkers@uantwerpen.be
Tel. Lab +32 3 265 26 05
Fax Lab +32 3 265 85 01

_____
_____
_____
Patients' personal data / hospital sticker

☐ **dd Depression or psych. disorder versus dementia (AD)**
☐ **dd Alzheimer's Disease (AD) versus non-AD neurocognitive disorder**

Proteins: tTau, $pTau_{181}$, $A\beta_{1-42}/A\beta_{1-40}$

Clin Chem Lab Med. 2021 Nov15;60(2):207-219

2x 1ml CSF + 2x 1ml EDTA Plasma (into 1,5ml PP tubes)
www.uantwerpen.be/sampling
Analysis cost: **125 euro**

☐ **ddCreutzfeldt-Jakob Disease (CJD) - NRC-RPD**

Proteins: 14-3-3 / PrPsc (RT-QuIC)

RT-QuIC inclusion only IF the diagnostic criteria 'possible CJD' according to the WHO/ECDC have been met OR 14-3-3 protein analysis returned (weak) positive. Acta Neurol Belg 2018 Sep;118(3):395-403

2x 1ml CSF + 2x 1ml EDTA Plasma (into 1,5ml PP tubes)
www.uantwerpen.be/sampling
Analysis cost: **no cost (due to NRC-RPD Consortium)**

☐ Opting out the use of residual CSF and/or plasma for further scientific research: **only tick the box if the patient makes objection.**

email Doctor: _____ Date: _____

Name Doctor: _____

RIZIV/INAMI nr: _____ Signature:

Name Hospital: _____ _____

Please complete specific clinical findings on next page.

Patient's name: _____ *Date of birth:* _____ *Date of CSF sampling:* _____

Clinical duration: ___ months
Age at onset: _____

☐ Rapid progressive neurodegeneration
☐ Slow progressive neurodegeneration

MMSE: _____ / 30 date: _____
ADAS-cog: _____

Clinical diagnosis: _____

Clinical symptoms at onset:

☐ Complaints of memory and/or orientation
☐ Behavioural symptoms
☐ Language difficulties
☐ Isolated visual symptoms
☐ Extra pyramidal onset
☐ Pure cerebellar onset
☐ Stroke-like onset
☐ Pure psychiatric onset
☐ Sensory symptoms at onset
☐ Other _____

Clinical remarks: _____

Clinical evolution:

Yes	No	?		Yes	No	?	
☐	☐	☐	**progressive dementia**	☐	☐	☐	limb apraxia
☐	☐	☐	memory disturbances	☐	☐	☐	**visuospatial dysfunction**
☐	☐	☐	orientation difficulties (space/time)	☐	☐	☐	hallucinations or delusions
☐	☐	☐	attention difficulties / distractibility	☐	☐	☐	REM sleep behaviour disorder
☐	☐	☐	behavioural changes: apathy	☐	☐	☐	falls
☐	☐	☐	behavioural changes: loss of empathy	☐	☐	☐	loss of consciousness
☐	☐	☐	behavioural changes: disinhibition	☐	☐	☐	**myoclonus**
☐	☐	☐	hyperorality	☐	☐	☐	frontal release signs
☐	☐	☐	perseverative / stereotyped / compulsive behaviour	☐	☐	☐	ataxia / **cerebellar signs**
☐	☐	☐	executive dysfunction	☐	☐	☐	**pyramidal signs**
☐	☐	☐	language difficulties / aphasia	☐	☐	☐	parkinsonism / **extrapyramidal signs**
☐	☐	☐	dysarthria	☐	☐	☐	depression
☐	☐	☐	**akinetic mutism**	☐	☐	☐	*psychiatric problems*
☐	☐	☐	verbal apraxia	☐	☐	☐	*epilepsia*

Neuro-imaging - if performed - thick when present

MRI / CT

☐ Normal
☐ Abnormalities - non specific
☐ Abnormalities - affecting striatum or neo-cortex
☐ High signal in caudate lobe and putamen
☐ High signal in posterior thalamus > other areas
☐ Enlargements - ventricular
☐ Atrophy - cerebral / Predominant regions / Global atrophy / Temporal atrophy

Predominant regions		Global atrophy	Temporal atrophy	
frontal	☐L ☐R	☐ GCA = 0	MTA 0	☐L ☐R
temporal	☐L ☐R	☐ GCA = 1	MTA 1	☐L ☐R
parietal	☐L ☐R	☐ GCA = 2	MTA 2	☐L ☐R
occipital	☐L ☐R	☐ GCA = 3	MTA 3	☐L ☐R
			MTA 4	☐L ☐R

other: _____

☐ Atrophy - cerebellar

PET FDG predominant hypometabolism

frontal	☐L ☐R
temporal	☐L ☐R
parietal	☐L ☐R
occipital	☐L ☐R

other: _____

PET Amyloid

☐ Neg
☐ Pos

EEG

☐ Normal
☐ Periodic sharp-wave complexes - triphasic
☐ Slowing focal or diffuse
☐ Slowing frontal or frontotemporal
☐ Slowed alfa activity
☐ Decreased beta activity
☐ Increased theta and delta activity
other: _____

<u>Additional information - Sciensano CJD Surveillance:</u>

Specific risk factors

Yes	No	?			
☐	☐	☐	Ever had a stroke	Year of stroke	_____
☐	☐	☐	Ever had a residence in UK	When	_____
☐	☐	☐	Ever had endoscopy	When / which hospital	_____
☐	☐	☐	Ever had surgery	Surgery info	_____
☐	☐	☐	Ever had neurosurgery	Neurosurgery info	_____
☐	☐	☐	Familial history of dementia	Dementia type	_____