NRC-ddCJD Consortium
National Reference Center rare disease [NRC] for Creutzfeldt-Jakob disease (ddCJD)

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Biological markers for neurodegeneration in Cerebrospinal Fluid (CSF) samples

To the attention of the patient or his representative: I was explained and understood the following:

☐ **I have been informed** about the cost of the analyses: analysis cost ddCJD: € 0 / analysis cost ddAD: € 125 (2024)
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** of the scientific added value in the pseudonymised storage and further use of my CSV residual sample in scientific research. If you would object to the use of these residual samples for future scientific biomarker research, please inform your doctor who will indicate this on the form. In case of accidental findings with serious effect on your health, you will be informed. 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 Neurobiobank ID BB1901113. 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.

☐ **I have been informed** that all data obtained will be kept strictly confidential and I retain the right to access and correct my data, cfr. https://www.uantwerpen.be/privacybeleid. I can decide at any time to no longer participate in this study. No new data will then be generated on the basis of your retained body materials. I can contact the undersigned physician for any further questions.

Optional only in case of ddAD diagnostics:

☐ **I agree** to non-diagnostic, prospective sampling and storage of a blood (plasma) sample for later use for scientific biomarker research. I have received a copy of the document 'Informed consent: prospective sampling and storage' document. (www.uantwerpen.be/icfprospect) Ref. EC/PM/AL/2021.020
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.

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

To the attention of the doctor:

NRC-ddCJD coordination / sample receipt / validation & communication of ddCJD results:
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
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_____
_____
_____
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 (2024)**
Ref. EC/PM/AL/2021.020 'prospective sampling and storage' (www.uantwerpen.be/icfprospect)

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

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 (into 1,5ml PP tubes)

Analysis cost: **no cost (due to NRC-ddCJD Consortium)**

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

Name Doctor: _____ Email Doctor: _____

RIZIV/INAMI nr: _____ Date: _____

Name Hospital: _____ Signature:

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	_____