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Informed Consent Form - Neurology

1 Patient

Informed consent is required for genetic testing. The patient (or parent or guardian in the case of minors under the age of 18 or adults lacking legal capacity) must sign the attached consent form. If the samples are anonymous, we will accept a statement from the physician responsible for the patient indicating that an appropriate informed consent has been obtained (section *"Statement of the existence of informed consent"*).

Patient's full name

2 Genetic study requested

NGS general panels

☐ Genetic Muscle Disorders (GMD)	264 genes	☐ Alzheimer's Disease and other Dementia	28 genes
☐ Hereditary Neuropathies	107 genes	☐ Amyotrophic Lateral Sclerosis / Primary Lateral Sclerosis	28 genes
☐ Spastic Paraplegia	76 genes	☐ Mitochondrial Nuclear Genes	174 genes
☐ Movement Disorders	123 genes	☐ Mitochondrial Genome	37 genes

Specific panels

Genetic muscle disorders

☐ Structural GMD	107 genes	☐ Metabolic Myopathies	113 genes
☐ Congenital Structural GMD	58 genes	☐ Glycogen Storage Myopathies	19 genes
☐ Child- and Adult-Onset Structural GMD	56 genes	☐ Lipid Storage Myopathies	15 genes
☐ Limb-Girdle Muscular Dystrophies	34 genes	☐ Mitochondrial Myopathies Nuclear Genes	79 genes
☐ Emery-Dreifuss Muscular Dystrophies	7 genes	☐ Non-Dystrophic Myotonias	8 genes
☐ Dystrophinopaties	[*DMD*]	☐ Arthrogryposis Comprehensive Panel	51 genes
○ MLPA ○ NGS Sequencing		☐ Multiple Pterygium Syndrome, Escobar Variant and Related Disorders	15 genes
☐ Distal Myopathies	31 genes	☐ Distal Arthrogryposis	10 genes
☐ Myofibrillar Myopathies	13 genes		
☐ Congenital Myasthenic Syndromes Comprehensive Panel	23 genes		
☐ Congenital Myasthenic Syndromes Core Panel	6 genes		

Hereditary neuropathies

☐ CMT Comprehensive Panel	63 genes	☐ CMT1A/HNPP Gene Dosage Analysis by MLPA	[*PMP22*]
☐ CMT - Demyelinating / Intermediate	30 genes	☐ Motor Neuropathy / SMN1-Negative Spinal Muscular Atrophy	30 genes
☐ CMT - Axonal / Intermediate	46 genes	☐ Hereditary Sensory and Autonomic Neuropathy	22 genes
☐ CMT - Deafness	21 genes	☐ Metabolic Neuropathy	18 genes
☐ CMT - Roma Population	3 genes		
☐ CMT - Core Panel	4 genes		

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Movement disorders

☐ Dystonia Comprehensive Panel	24 genes	☐ Chorea and Huntington-like Disorders	19 genes
☐ Primary Dystonia	8 genes	☐ Basal Ganglia Calcification	11 genes
☐ Dopa-Responsive Dystonia	3 genes	☐ Aicardi-Goutières Syndrome Specific Panel	7 genes
☐ Myoclonus-Dystonia	3 genes	☐ Neurodegeneration with Brain Iron Accumulation Syndromes (NBIAS)	10 genes
☐ Parkinson and Related Disorders Comprehensive Panel	15 genes	☐ Metabolic Movement Disorders	32 genes
☐ Parkinson's Disease	7 genes	☐ Neuronal Ceroid Lipofuscinosis Specific Panel	11 genes
☐ Young-Onset Parkinson's Disease	6 genes	☐ Paroxysmal Movement Disorders	18 genes

Hereditary spastic paraplegia

☐ Pure Spastic Paraplegia	28 genes	☐ Spastic Paraplegia Core Panel	8 genes
☐ Complicated Spastic Paraplegia	65 genes		

Mitochondrial disorders

☐ Mitochondrial Respiratory Chain Complex Deficiency	45 genes	☐ Pyruvate Dehydrogenase (PDH) Deficiency	12 genes
☐ mtDNA Depletion	16 genes	☐ Primary Coenzyme Q Deficiency	11 genes
☐ Nuclear Gene-Encoded Leigh Syndrome Core Panel	14 genes		

Nucleotide repeat expansion analysis

☐ Myotonic Dystrophy Type 1 [*DMPK*]	☐ Friedreich's Ataxia [*FXN*]
☐ Oculopharyngeal Muscular Dystrophy [*PABPN1*]	☐ *C9orf72* [ALS/FTD]

Complementary services

☐ Single Gene Sequencing

Gene ..... Gen .....

☐ Familial Studies

Gene/variant ..... Gene/variant .....

☐ Study extension

Specify the name of the new panel: .....

☐ Other services

.....

The personal data provided in this form are subjected to the current data protection regulations, specifically to Regulation UE 2016/679 of the European Parliament and of the Council of 27 April 2016 and to Law 14/2007, of 3 July, on. Biomedical Research. The data you provide will be included in files whose responsible is Health in Code.

The **purpose** is the analysis and diagnosis of genetic disease. Likewise, the **data categories** are the ones reflected in this form, along with the results obtained.

Your personal data will be treated exclusively for the aforementioned purposes. This treatment is **legitimate** based on the express consent provided by accepting these terms.

Your **data will be retained** for the whole duration of the relationship established with the entity and while the data fulfil their purposes for this service, or until you decide to exercise your cancellation or suppression rights. These data will not be transferred to third parties without previous consent or outside the cases expressly provided for in the current data protection regulations.

You are hereby informed that you may exercise your **rights to access, rectification, cancellation, and objection, as well as to restriction of data processing and to data portability** by contacting Health in Code, through written communication addressed to Edificio O Fortín, As Xubias, s/n., Campus de Oza, 15006 A Coruña, España, with the subject: "Data protection", including a copy of your national ID card or passport.

You also have the right to file your claim to the Spanish Data Protection Agency (Agencia Española de Protección de Datos).

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3 Patient's authorization

I declare that I have been informed of, that I understand, and that I am in agreement with the type of genetic study indicated above and in which I am voluntarily participating.

I understand that I may be affected by or be a carrier of a hereditary genetic disorder, the diagnosis of which may be confirmed by a laboratory study analyzing DNA obtained from my biological samples. I hereby give my consent to have my sample sent to Health in Code S.L., a company with a level of data protection in accordance with European legislation, to carry out the indicated genetic study, as well as to the center or centers designated by it, complying with ethical considerations and current legal regulations:

☐ Yes ☐ No

I understand that:

- Genetic disorders may be inherited by family members and that the results of my test may have implications for my own family.
- In the case of a genetic study of a mutation, the determination of the mutation is diagnostic, while non-determination does not exclude the pathology. A negative test does not exclude the possibility of having the disease (some diseases have multiple causes and it is not possible to test for all of them).
- Occasionally, there may be unusual alterations in the DNA structure of certain individuals that may yield results that are difficult to interpret, making the diagnosis difficult and even making it impossible to obtain conclusive results.
- Although the methods used to perform this diagnostic testing are extremely sensitive and specific, there is always a small chance of failure of the technique or of an interpretation error. For this reason, repeating the test or performing additional ones may be necessary in some cases, which may or may not require obtaining new samples, particularly in those cases where quality of the biological sample is suboptimal.
- Given the complexity of genetic studies based on DNA and the important implications of the results of a genetic study, I will be informed of said results by a physician or genetic expert, always with the highest confidentiality level from both medical and laboratory personnel.
- I may change my mind at any time and withdraw the authorization for the genetic study given by me in this document, thereby revoking my decision to continue with the analysis.
- The only people who will have access to the test results will be members of the Health in Code, S.L. team and health service professionals involved in patient care.
- It is possible to obtain unexpected information during the sample analysis process, and I hereby declare that I want to be informed about it:

☐ Yes ☐ No

- It is possible that information concerning the relatives of the sample donor will be obtained. We recommend that the latter (or his/her legal representative) should be the person who shares said information. In any event, the approval of each family member will be required.

Current legislation requires Health in Code, S.L. to keep clinical documentation under conditions that ensure its proper maintenance and security for purposes of due patient care for at least five years after the assistance process has ended. I am aware and accept that a DNA aliquot will be kept in the laboratory for subsequent studies and/or confirmation tests:

☐ Yes ☐ No

In addition, I consent to the biological sample being used by the entity Health in Code, S.L. for research purposes approved by the relevant ethics committee after the termination of the study, always maintaining the patient's anonymity.

☐ Yes ☐ No

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In which case, you are informed of:

- The purpose of the research related to the pathology whose diagnosis is intended and to other related lines of research.
- The expected benefits of the research, which will consist of a greater understanding of the pathologies studied, their development, and related population studies.
- The possibility that you will be contacted later for the purpose of collecting new data or obtaining new samples.
- The right to revoke this consent at any time and without any justification whatsoever and to decide to have the sample destroyed or anonymized.
- The obligation of Health in Code, S.L. to destroy or anonymize the sample once the research has finished and after the statutory storage period, unless authorization for longer storage has been given.
- Your right to know the genetic data obtained from the analysis of your biological samples.
- The confidentiality of the information obtained, with solely members of the Health in Code, S.L. research team having access to personal data.
- The possibility that information concerning the relatives of the sample donor may be obtained. We recommend that the latter (or his/her legal representative) be the person who shares said information. In any event, the approval of each family member will be required.

If applicable, I hereby authorize the extraction of biological samples and the genetic study of dependent minor/s in my care to be used under the terms and conditions previously described for the genetic test for the aforementioned disease.

Name of the patient or legal representative*
**If the patient is a minor or lacks legal capacity*

National Identification Number of the patient or legal representative

Signature of patient or legal representative

Date

4 Statement of the existence of informed consent

☐ I hereby declare that the patient identified on this request is aware of the information on said request and has signed the Informed Consent form to permit this genetic study to be carried out and that this has been included in his/her clinical record.

Physician's signature

Date

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