



**Declaration of Informed Consent  
for the Scientific Use of Blood and Tissue  
and Personal Data**

Dear Ms. \_\_\_\_\_ / Dear Mr. \_\_\_\_\_,

We herewith request your informed consent to the scientific use of your blood and tissue samples and your personal data as described to you in detail in the information for test persons.

**European Epilepsy Brain Bank for the acquisition of tissue and data  
from patients suffering from hard-to-treat epilepsy in the scope of the  
European DESIRE Consortium**

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*A. General*

I have been orally informed by the study physician about the purpose, procedures and rationale of the clinical study and of the possible benefits and risks involved. I have read the written information for test persons. All my questions have been answered to my satisfaction.

I have received a copy of the information for test persons and of the declaration of informed consent. I had sufficient time to consider and freely make my decision to participate in the study.

My following declarations extend only as far as I was informed of the nature of the study in the written information for test persons and the oral explanation.

My following declarations entitle and obligate the aforementioned institute.

## **B. Consent to the recovery and use of blood and tissue samples**

*(Please check as appropriate)*

**B 1** I consent to the **removal** of blood and tissue samples and herewith donate the blood and tissue samples removed to the aforementioned institute.

I **agree** that under the responsibility of the aforementioned institute use be made of the blood and tissue samples in encrypted form (so that it is only possible to link the data to my person by using additional tools such as a reference list)

- For studies concerning the abovementioned research question.
  - I agree that I may be contacted (as far as possible) by the aforementioned institute to request my consent to the use of my blood and tissue samples in other studies.

**or**

- I demand today that my blood and tissue samples be destroyed upon termination of the abovementioned studies.

**or**

- For studies concerning **all** scientifically relevant research questions.

### **B 2 [TRANSFER TO THIRD PARTIES]**

I agree to the transfer of my blood and tissue samples to the following: members of the European DESIRE Consortium (see attachment). The abovementioned limitations to my consent also apply here.

I do not agree to the transfer.

### **B 3 [INFORMATION ABOUT STUDY RESULTS]**

I would like to be informed of any results of the abovementioned study insofar as they are of direct significance for me and my close family.

**or**

I agree that I do not receive any personal feedback about the results of the study.

#### **B 4 [NON-REMUNERATION]**

I am fully aware that I do not receive any remuneration for the donation of my blood and tissue samples.

I am fully aware that I have no right to remuneration, bonuses or any other participation in financial benefits and gains which might result from the research using my blood and tissue samples.

#### **B 5 Withdrawal of Consent to Use Samples**

I know that I can withdraw at any time without giving reasons my consent to the abovementioned institute/person to use my blood and tissue samples and that this does not in any way affect the continuation of my medical treatment.

In the case of withdrawal of my consent I herewith agree that my blood and tissue samples will be kept for control purposes. However, I do have the right to demand that they be destroyed insofar as there are no statutory stipulations against such destruction.

I am fully aware that destruction of the blood and tissue samples is not possible on my request if they are so encrypted (anonymized) that it is not possible to establish a connection between the said samples and my person or that it would be possible only at disproportionately high costs in time, money and labor.

**C. Declaration of Consent concerning Data Protection** *(Please check as appropriate)*

I herewith agree that the aforementioned person or an employee of the aforementioned institute has access to my original medical records.

I agree that the data concerning my person (also including in particular illness data from my medical records) may under the responsibility of the aforementioned institute and in encrypted form

Be stored and processed for studies concerning the abovementioned research question.

**or**

Be stored and processed for studies concerning **all** scientifically relevant research questions.

**[TRANSFER OF DATA TO THIRD PARTIES / ACCESS TO DATA BY THIRD PARTIES]**

I herewith agree that other persons may have access to my original medical records *(where appropriate primarily the names of the employees of the party commissioning the study should be listed):* .....

I agree to the transfer of my data in encrypted form to the following institute/persons: members of the DESIRE Consortium (see attachment).

**Withdrawal of Consent to Use Data**

I know that I can withdraw at any time without giving reasons my consent to the abovementioned institute/person to use my data and that this does not in any way affect the continuation of my medical treatment.

In the case of withdrawal of my consent I herewith agree that my data will be stored for control purposes. However, I do have the right to demand that the data be deleted insofar as there are no statutory stipulations against such deletion.

I am fully aware that in the case of anonymized storage of my data it is not possible to delete such data on my request.

Date

Name of the test person

Signature

## A2: List of Beneficiaries

Project Number <sup>1</sup>		Project Acronym <sup>2</sup>		DESIRE	
602531					
List of Beneficiaries					
No	Name	Short name	Country	Project entry month <sup>10</sup>	Project exit month
1	UNIVERSITA DEGLI STUDI DI FIRENZE	UNIFI	Italy	1	60
2	FONDAZIONE IRCCS ISTITUTO NEUROLOGICO CARLO BESTA	FINCB	Italy	1	60
3	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE (INSERM)	INSERM	France	1	60
4	UNIVERSITAETSKLINIKUM ERLANGEN	UKER	Germany	1	60
5	UNIVERSITA DEGLI STUDI DI VERONA	UNIVR	Italy	1	60
6	CENTRE NATIONAL DE LA RECHERCHE SCIENTIFIQUE	CNRS	France	1	60
7	FONDAZIONE ISTITUTO ITALIANO DI TECNOLOGIA	IIT	Italy	1	60
8	AGENCIA ESTATAL CONSEJO SUPERIOR DE INVESTIGACIONES CIENTIFICAS	CSIC	Spain	1	60
9	KING'S COLLEGE LONDON	KCL	United Kingdom	1	60
10	CHARITE - UNIVERSITAETSMEDIZIN BERLIN	CHARITE	Germany	1	60
11	KLINIKUM DER UNIVERSITAET ZU KOELN	UKK	Germany	1	60
12	UNIVERSITY COLLEGE LONDON	UCL	United Kingdom	1	60
13	THE UNIVERSITY OF LIVERPOOL	LIV	United Kingdom	1	60
14	UNIVERSITE LIBRE DE BRUXELLES	ULB	Belgium	1	60
15	CHRISTIAN-ALBRECHTS-UNIVERSITAET ZU KIEL	CAU	Germany	1	60
16	BAKER IDI HEART AND DIABETES INSTITUTE HOLDINGS LIMITED	BAKER IDI	Australia	1	60
17	UNIVERSITA TA MALTA	UOM	Malta	1	60
18	DI.V.A.L. TOSCANA SRL	DIVAL	Italy	1	60
19	MICROMED S.P.A.	MMED	Italy	1	60
20	VARIONOSTIC GMBH	VAR	Germany	1	60
21	CEGAT GMBH	CEGAT	Germany	1	60

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No	Name	Short name	Country	Project entry month <sup>10</sup>	Project exit month
22	AMARNA THERAPEUTICS BV	Amarna	Netherlands	1	60
23	CF CONSULTING FINANZIAMENTI UNIONE EUROPEA SRL	Cfc	Italy	1	60
24	UNIVERSITA CATTOLICA DEL SACRO CUORE	UCSC	Italy	1	60
25	OSPEDALE PEDIATRICO BAMBINO GESU	OPBG	Italy	1	60