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|  |  | **Administration Office**  c/o EMQN CIC, Unit 4, Enterprise House,  Manchester Science Park, Pencroft Way,  Manchester M15 6SE, United Kingdom.  **Tel:** +44 161 757 4952  **Fax:** +44 161 850 1145  **Email:** [admin@erndim.org](mailto:admin@erndim.org) |

# **Consent form for the use of patient samples for External Quality Assurance**

## Patients’s copy – *please give to patient/parent/legal guardian to keep*

As part of the laboratory process of testing for metabolic disorders samples from patients with known diagnoses are circulated to laboratories to test and report their findings to ERNDIM. Laboratories then receive feedback on their performance. This is an extremely valuable process that helps laboratories across Europe maintain high standards.

The samples will be anonymised before use and ERNDIM will not be sent any of your/your child’s personal data. We would be very grateful for your help in providing these samples; however, you are under no obligation to agree to do so.

If you agree to provide a sample for this purpose can you please sign this form below.

I consent to the use of a …………….sample from …………….………………aged…….…yrs for quality assurance purposes to contribute to the continuing reliable provision of diagnostic services for ……………………………………………………

Signed ……………………………………....................(Patient/Parent/Legal Guardian) *please select*

Print Name ……………………………………………..

Date …………………………

Consent taken by:

Signed …………………………………………..............(Clinician)

Print Name ……………………………………………….

Institution ………………………………………………….

Date …………………………

Local Reference Number \*………………………………

*(please do not use the patient’s name)*

\* = This local reference number will not be used by ERNDIM but may be required by the donating clinician, who may use it if they need to contact you in the future.

Requests for further information or future concerns can be addressed to ERNDIM Administration Office, c/o EMQN CIC Office, Unit 4, Enterprise House, Pencroft way, Manchester Science Park, Manchester, M15 6SE, United Kingdom.

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**Consent form for the use of patient samples  
for External Quality Assurance**

## Local copy – *please file this copy with the patient’s notes*

As part of the laboratory process of testing for metabolic disorders samples from patients with known diagnoses are circulated to laboratories to test and report their findings to ERNDIM. Laboratories receive feedback on their performance. This is an extremely valuable process that helps laboratories across Europe maintain high standards.

The samples will be anonymised before use and ERNDIM will not be sent any of your/your child’s personal data. We would be very grateful for your help in providing these samples; however, you are under no obligation to agree to do so.

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Signed ……………………………………....................(Patient/Parent/Legal Guardian) *please select*

Print Name ……………………………………………..

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Signed …………………………………………..............(Clinician)

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Institution ………………………………………………….

Date …………………………

Local Reference Number \*………………………………

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# **Confirmation of Informed Consent for the use of patient samples for External Quality Assurance**

## To be completed by the donating Clinician

I confirm that the patient sample detailed below was collected with the informed consent of the patient/ parent/ legal guardian (please select) and that all local ethical guidelines were followed.

|  |  |
| --- | --- |
| Signature: |  |
| Print Name |  |
| Position: |  |
| Date: |  |
| Hospital Name: |  |
| Hospital Address: (including country) |  |
|  |
|  |

**Sample Details *(do not include patient personal information in this form)***

|  |  |
| --- | --- |
| Local reference number \*: |  |
| Diagnosis |  |
| Sex: |  |
| Age at diagnosis: |  |
| Testing used to establish diagnosis:  (e.g. metabolite, enzyme or mutation testing) |  |
| Age at sampling: |  |
| Current therapy: |  |
| Clinical details: |  |
|  |
|  |
|  |

***\**** *= please use the same local reference number as given on the signed consent forms, which should not be the patient name.*

Please return this page only of the completed form to:

ERNDIM Administration Office, c/o EMQN CIC Office, Unit 4, Enterprise House, Pencroft way, Manchester Science Park, Manchester, M15 6SE, United Kingdom Tel: +44 (0)161 757 4952, Fax: +44 (0)161 850 1145, Email: admin@erndim.org

Requests for further information or future concerns can be addressed to the ERNDIM Administration Office at the address above.

Data Protection

* By signing this form you, the donating clinician, are agreeing that ERNDIM can process, share and store your personal data only for the purposes of processing the donated sample described in this form.
* As the donating clinician, any of your own personal information you supply to ERNDIM on this form will be treated in accordance with the ERNDIM Privacy Policy (which can be found on [www.erndim.org](http://www.erndim.org/)) and the UK’s Data Protection Act 2018,which is the UK’s implementation of the EU General Data Protection Regulation (GDPR) 2016. **Do not include any partient personal information in this form.**
* We will only communicate with you or share your data with a third party for purposes related to processing this sample donation unless you have consented elsewhere that we can contact you or share your data for other reasons.
* We will not share your data with third parties for marketing purposes.