



Parent/Guardian – Patient Consent Form

The EpiFUN study: Correlations between phenotype, genotype and functional analysis in the (neuro)genetic disorders of childhood

- Part 1: CINDI Registry (confirmed genetic diagnosis)

Part 1: CINDI Registry

I consent to my child partaking in Part 1 of this study having been informed of the risks, benefits and alternatives. I am happy for information to be stored on the CINDI registry.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I give permission for researchers to look at my child's medical records to get information, this will include genetic results. I have been assured that information about my child will be kept private and confidential.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to being re-contacted should a treatment, trial or study become available that may be of interest to my child.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

I have read and understood the Information Leaflet about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my child does not have to take part in this study and that we can opt out at any time. We understand that we don't have to give a reason for opting out and I understand that opting out won't affect my child's future medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am aware of the potential risks, benefits and alternatives of this research study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I give informed consent to have my child's data processed as part of this research study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that coded information may be shared with other institutions, databases and partners with whom we have a research collaboration.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand information from the study added to my clinical record may be uploaded to clinical databases in a de-identified form (including genomic sequences).	Yes <input type="checkbox"/>	No <input type="checkbox"/>

STORAGE AND FUTURE USE OF INFORMATION		
I give permission for my child's data to be stored for <i>possible future health research</i> if research is approved by a Research Ethics Committee.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If answered Yes for storage for future research - I agree to future research if approved by a research ethics committee	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If answered Yes for storage for future research - I agree to future research	Yes <input type="checkbox"/>	No <input type="checkbox"/>

by a commercial/pharmaceutical company if approved by a research ethics committee		
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Child's Name (Block Capitals)

Parent/Guardian's Name (Block Capitals) | Parent/Guardian's Signature | Date

Parents email address:

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Name (Block Capitals) | Qualifications | Signature | Date

3 copies to be made: 1 for patient, 1 for PI and 1 for hospital records.