

STUDY NAME: **ENDURE**

CI: Professor Andrew Hattersley

Understanding beta cell disorders through the
study of rare genotypes

Version: 2 01 May 2024

Participant ID:

Parent / Guardian of Participants

CORE STUDY CONSENT STATEMENTS (applicable to all participants)	Please circle answer	Please initial
I have been given the ENDURE Core Study information leaflet [Version, dated/...../.....].	YES / NO	
I have had the opportunity to ask questions, and these have been answered fully.	YES / NO	
I agree to: <ul style="list-style-type: none"> my child attending an appointment(s) as detailed in the ENDURE study information leaflet. 	YES / NO	
<ul style="list-style-type: none"> provide information about my child's health for use in this study. 	YES / NO	
<ul style="list-style-type: none"> allow the research team to contact my child's clinicians/GP about their clinical care now and in the future. 	YES / NO	
<ul style="list-style-type: none"> my child's de-personalised samples and data being shared to support future research in and outside the UK, including with commercial partners. 	YES / NO	
<ul style="list-style-type: none"> my child's samples and data being stored for the duration of the study. 	YES / NO	
I agree to: <ul style="list-style-type: none"> my child providing blood samples for analysis, including genetic studies using DNA, as detailed in the ENDURE study information leaflet. 	YES / NO	
I understand that: <ul style="list-style-type: none"> my child's participation is voluntary and that I may withdraw them at any time without my child's clinical care being affected. 	YES / NO	
<ul style="list-style-type: none"> my child's samples and data are provided as a gift to the ENDURE study team and neither my child nor I will benefit financially should there be a future discovery or invention. 	YES / NO	
<ul style="list-style-type: none"> individuals from the study team, regulatory authorities or the UK NHS Trust will have access to relevant sections of my child's medical notes and data collected during the study for research, monitoring and audit purposes. 	YES / NO	
<ul style="list-style-type: none"> my child's research data and samples will be stored securely using an ID format to protect their identity. 	YES / NO	
<ul style="list-style-type: none"> my child's clinical samples will be sent for testing at the Exeter Clinical Laboratories, together with three forms of identifiable information (name, DOB, NHS/CHI/hospital number) in accordance with the NHS requirements for clinical sample analysis. 	YES / NO	
<ul style="list-style-type: none"> results produced by studying my child's samples and/or data may be included in publications with no connection to their name or other personal identifiers. Results may also be placed in electronic archives only accessible to researchers on application, to ensure the results are only used to advance scientific and medical understanding. 	YES / NO	
I agree to my child taking part in the ENDURE Core Study.	YES / NO	
Continued overleaf	YES / NO	



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IMAGING SUB-STUDY CONSENT STATEMENTS <i>(This is an additional sub-study which is only relevant if your child is invited to it.)</i>	Please circle answer	Please initial
My child has been invited to take part in the Imaging Sub-Study.	YES / NO	
I have been given the ENDURE Imaging Sub-Study Flowchart [Version ..., dated/...../.....].	YES / NO	
I have had the opportunity to ask questions, and these have been answered fully.	YES / NO	
I agree to: <ul style="list-style-type: none"> my child attending an appointment(s) as detailed in the Imaging Sub-Study Flowchart that comes with the ENDURE core study information leaflet. my child having an MRI scan (as detailed in the Imaging Sub-Study Flowchart) at the Mireille Gillings Neuroimaging Centre (University of Exeter). relevant sections of my child's medical notes and data collected during the study being accessed by responsible individuals from the University of Exeter, or the appointed service providers and NHS Trusts, or regulatory authorities, where it is relevant to my taking part in the research. I give permission for these individuals to access my child's records. my child's data being stored for the duration of the study. 	YES / NO	
• I understand that data collected during my child's participation in the Imaging Sub-Study will be stored electronically on secure systems, and in secure paper formats, by the Mireille Gillings Neuroimaging Centre (University of Exeter).	YES / NO	
I agree to my child taking part in the ENDURE Imaging Sub-Study.	YES / NO	
OPTIONAL CONSENT STATEMENTS <i>(applicable to all participants)</i>		
I agree to gift my child's samples and data from the study, for storage and future research to the Genetic Beta Cell Research Bank, managed by The Royal Devon University Healthcare NHS Foundation Trust's Exeter Genomics Laboratory.	YES / NO	
I agree that information held by the Exeter Genomics Laboratory and in my child's medical records may be used to follow up on my child's future health status.	YES / NO	
I agree to be contacted by the study team about my child taking part in future studies.	YES / NO	
PARTICIPANT'S NAME (PRINT)		
PARENT'S/GUARDIAN'S NAME (PRINT)	TELEPHONE CONSENT DATE:	
PARENT'S/GUARDIAN'S NAME (SIGNED)	VISIT CONSENT DATE:	
RESEARCHER / CLINICIAN I confirm that I have obtained informed consent from the above person who is the parent or acts as guardian for the participant.		
NAME (PRINT)	TELEPHONE CONSENT DATE:	
SIGNED	VISIT CONSENT DATE:	

When completed: 1 for participant; 1 for researcher site file; 1 for MGNC (if applicable).