

New Sites – Questionnaire

Name of Institution	
Address	
Main Investigator	Name: Position: E-Mail: Tel: Fax:
Study nurse / other contact	Name: Position: E-Mail: Tel: Fax:
<input type="checkbox"/> I agree with the publication of my above mentioned contact details on project-related websites (mitoNET.org and GENOMIT.eu) and patient flyers.	
Current CV	Attached <input type="checkbox"/>
Fluent in English?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Current mitochondrial research?	Please list or add as attachment:
Relevant publications within the mitochondrial field?	Please list or add as attachment.

Current mitochondrial patients	Type CPEO/KSS LHON MELAS/MERRF Leigh syndrome Other: _____ Other: _____ Other: _____	Number of Patients ¹ _____ _____ _____ _____ _____ _____
Yearly follow-up possible?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Computer with Internet Access available	<input type="checkbox"/> Yes <input type="checkbox"/> No	
IRB requirements (we can provide draft German and/or English documents, but the site has to adjust as per local requirements / translate to local language and submit to IRB)	Can you submit documents to your local IRB in German or English? (e.g. protocol, SOPs etc.) <input type="checkbox"/> Yes <input type="checkbox"/> No If not (or partly), can you translate the documents from German/English to local language? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, who will translate them: <input type="checkbox"/> study member, fluent in German / English <input type="checkbox"/> translation company (<i>costs to be covered by the site</i>)	
Confidentiality agreement (CDA)	Accepted in German/English? <input type="checkbox"/> Yes, German <input type="checkbox"/> Yes, English <input type="checkbox"/> No To be signed at site by: <input type="checkbox"/> legal department and investigator <input type="checkbox"/> investigator only	
Clinical study agreement (CSA)²	Needed at site prior IRB submission? <input type="checkbox"/> Yes <input type="checkbox"/> No To be signed at site by: <input type="checkbox"/> legal department and investigator <input type="checkbox"/> and by: _____ Site accepts: <input type="checkbox"/> only originals <input type="checkbox"/> Scanned contract versions In case of originals only: how many originals are required? _____	

¹ At least 5 mitochondrial patients with yearly follow-up visits should be included into the registry / biobank.

² Payment for patient recruitment can be provided until April 2022 to German mitoNET sites only

Willing to participate in Biobank?	<div><input type="checkbox"/> Yes <input type="checkbox"/> No</div> <p>If Yes:</p> <p>Is there a centrifuge for samples processing at 2000g and 4°C?</p> <div><input type="checkbox"/> Yes <input type="checkbox"/> No</div> <p>Is there a possibility to store samples at -80°C, also for a longer period of time?</p> <div><input type="checkbox"/> Yes <input type="checkbox"/> No</div> <p>Is your site able to cover shipment costs³ for the samples to Germany (dry ice shipment) with own recourses?</p> <div><input type="checkbox"/> Yes <input type="checkbox"/> No</div>
Comments	

³ current mitoNET sites are exempt from these costs until April 2022.