Universitätsklinikum Leipzig
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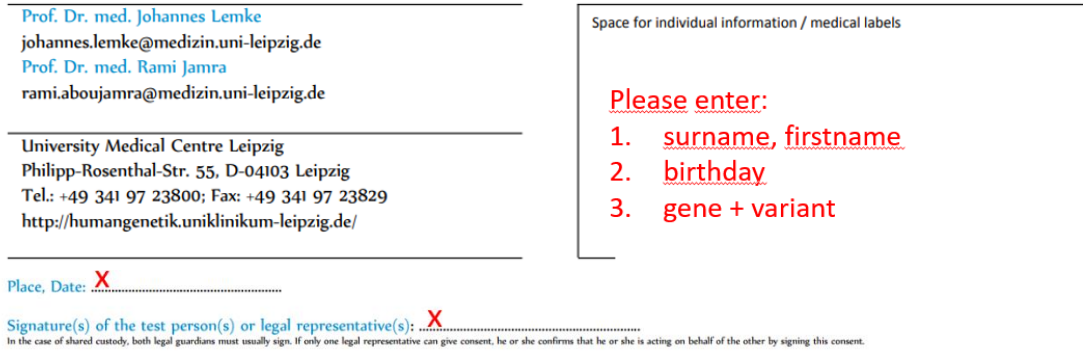
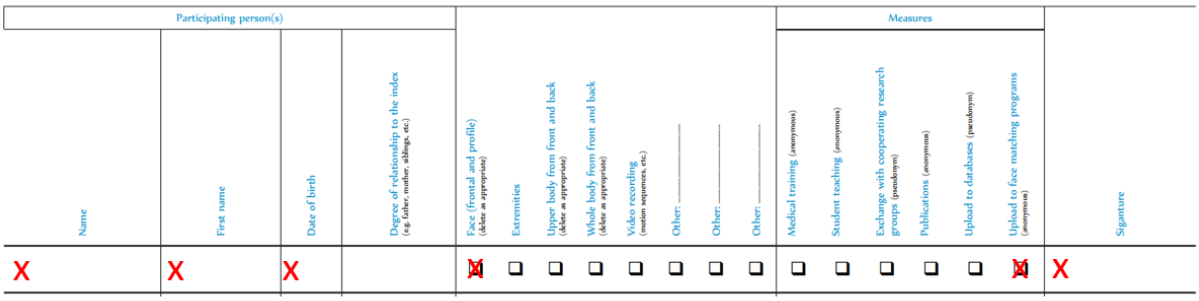
Leipzig, 28.04.2023 ViS

Dear GRI(N) families, dear colleagues,
Our group is conducting a joint research project with Gestaltmatcher. The aim is to use deep phenotyping technology to determine whether patients with GRI(N)-associated diseases have recognizable facial abnormalities that could play a role in the diagnosis.
We would be very pleased if you could participate in the project. For this purpose we need a biometric photo of the face of the affected patient and a consent for our research project (See attachment).

Please fill in the following spaces on the consent form:
11
Page 1:



Page 2:



Please send the photo and scan of the completed consent to the following mail address:
GRIN@medizin.uni-leipzig.de

Thanks for your participation!

With best regards from Leipzig
Vincent Strehlow and Johannes Lemke

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UZSEL – ZENTRUM FÜR SELTENE ERKRANKUNGEN LEIPZIG

UNIVERSITÄT LEIPZIG
Medizinische Fakultät

Informed Consent for video and photo documentation

on the study

Genetics of rare diseases based on Next Generation Sequencing

at the Institute of Human Genetics and the Centre for Rare Diseases of the University Medical Centre Leipzig

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Space for individual information / medical labels

General

Within the framework of the above-mentioned study, it is planned to carry out video and photo documentation of the test persons. I can decide to what extent this should be carried out. All my questions were answered to my complete satisfaction. I had enough time to think about and freely make the decision to participate in the video and photo documentation. The participation in the video and photo documentation is voluntary and free of charge, there are no claims for payment or remuneration, royalties or other participation in financial benefits and profits that may be obtained on the basis of the research with our data.

Data protection and revocation

I agree that videos and photographs relating to the characteristics specified in the table on the following page may be recorded under the responsibility of the persons or employees of the institution named at the beginning of this document and stored in the study database in encrypted form by means of an identification number (ID). In addition, I agree that the image material may be exchanged pseudonymously with cooperation partners and project leaders involved in the study and may be used in pseudonymous form for publications and publications of the study results.

I know that this consent for the use of the videos or photographs can be revoked at any time and without giving reasons vis-à-vis the persons or employees of the institution mentioned at the beginning and that this has no influence on any further study participation or medical treatment. This consent is valid until revoked by the participants.

Protection of children and those in need of protection

I have been informed that I am required to tell the persons legally represented by me from the age of 14 years about the video and photo documentation of this study and to present it to the project leader or a member of the project staff in person or by telephone, if requested, in order to answer any questions. If the subject reaches the age of 18 during the course of the study, a new informed consent must be given with regard to the video and photo documentation. In the case of subjects who are unable to give their consent independently (the majority of subjects), this will continue to be decided by the parents or legal representatives.

Place, Date: .....

Signature(s) of the test person(s) or legal representative(s): .....

In the case of shared custody, both legal guardians must usually sign. If only one legal representative can give consent, he or she confirms that he or she is acting on behalf of the other by signing this consent.

If applicable, notes or comments from the informing physician or from the subject or his relatives:

Informed Consent

I hereby confirm by ticking the following options that I consent to the corresponding video and photo documentation. No cross or a missing signature is considered as not given consent.

Participating person(s)												Measures						
Name	First name	Date of birth	Degree of relationship to the index (e.g. father, mother, siblings, etc.)	Face (frontal and profile) (delete as appropriate)	Extremities	Upper body from front and back (delete as appropriate)	Whole body from front and back (delete as appropriate)	Video recording (motion sequences, etc.)	Other:	Other:	Other:	Medical training (anonymous)	Student teaching (anonymous)	Exchange with cooperating research groups (pseudonym)	Publications (anonymous)	Upload to databases (pseudonym)	Upload to face matching programs (anonymous)	Siganture
				❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	
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....

Name / stamp of the informing physician:

....

Place, date and signature of the informing physician: