

Center for Rare Diseases Aachen  
Center for Human Genetics and Genomic Medicine

## Computer-Assisted Image Analysis in the Diagnosis of Genetic Disorders (PEDIA AC)

### Declaration of Consent

I have read the information material about the research study "Computer-Assisted Image Analysis in the Diagnosis of Genetic Disorders" (abbreviated: PEDIA AC), or it has been read to me, and I have been informed about my rights as a data subject. I had the opportunity to ask questions, and all questions I asked were answered to my satisfaction. I have the right to request further information about the project at any time.

I voluntarily consent [on behalf of my child / the person in my care] to participate in this study. I have been informed that I may withdraw my consent at any time and without giving any reason.

In the event of withdrawal of consent, all attributable data will be deleted, and this decision will not negatively affect me in any way.

I am willing to participate in the study and to provide my image data as well as encrypted clinical and genetic data for this purpose.

I understand that the images may be seen by medical and scientific professionals who use the databases. Although these images are used without identifying information, such as my name, I understand that someone may recognize me. I also agree that my images may be used for training purposes for human and artificial intelligence. This includes the education of medical students and resident physicians, as well as machine learning.

[ ] I hereby voluntarily consent to the collection and processing of my personal data as described above. I have been sufficiently informed and had the opportunity to ask questions. I have been informed about the consequences of revoking my data protection consent. I have received the written information and consent form.

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#### In addition, please tick the applicable items:

[ ] I consent to access to the images and non-personal data in a computer-assisted image analysis database by medical professionals from other institutions. This allows the data to also be used by other institutions for similarity comparisons of their patients and for training artificial intelligence algorithms. Although these photos are used without identifying information, such as my name, I understand that someone may recognize me.

[ ] I agree that the images published in a database by me or my child / the person in my care may be used for teaching and educational purposes. This includes the training of medical students and resident physicians.

[ ] I agree that my images and data may additionally be published in anonymized form in a scientific journal. My personal data are subject to data protection law.

[ ] I would like to be contacted again if necessary for publication in scientific journals.

[ ] This study may be followed by scientific follow-up investigations. I agree that I may be contacted again for scientific follow-up investigations if necessary.

If you consent to being recontacted for journal publication or scientific follow-up investigations, please leave your contact details:

Contact details for recontact (name, phone / e-mail): \_\_\_\_\_

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### Patient

Name: \_\_\_\_\_

First name: \_\_\_\_\_

Date of birth: \_\_\_\_\_

### Signee

Name: \_\_\_\_\_

First name: \_\_\_\_\_

Signing on behalf of: \_\_\_\_\_

☐ Self

☐ My child

☐ Legal dependent

Place: \_\_\_\_\_

Date: \_\_\_\_\_

**Signature**

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