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Hamburg-Eppendorf

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To
Canavan families

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Canavan Natural History Study

Dear Family,

We invite you to participate in a research study investigating the clinical course of Canavan disease and factors having a good or bad influence on the disease course.

Enclosed you will find an **information letter**, an **informed consent form** and a **questionnaire** concerning the course of your child's leukodystrophy.

Your participation in this study will help us better understand Canavan disease and why patients with the same disease often have a quite different course. Such knowledge is a prerequisite for evaluating new experimental therapies and assessing the effectiveness of palliative measures. If you decide to participate, which we seriously hope, please:

Fill out the questionnaire to the best of your knowledge. Perhaps you will not be able to answer all questions, because you may need information from your physician or you don't remember details, or the question does not seem to suit your child. If you are uncertain with an answer, just leave it out. It would also be helpful if you would enclose medical letters giving the proof of diagnosis and further information of the course of the disease. If you allow us to do this, we may contact you or your physician to clarify eventual uncertainties.

Please return the completed questionnaire and signed consent form (envelope enclosed). Please do not hesitate to contact us for any questions and concerns.

With kind regards from Hamburg,

Alfried Kohlschuetter, MD
Professor of Pediatrics

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