

## Request for associations regarding Pain Questionnaire

Research title: Pain in Williams, Prader-Willi, and Fragile X syndromes

Amsterdam, 13 april 2017

Dear Sir / Madam,

Researchers at the VU University examine pain characteristics (the presence of painful conditions, pain perception, pain behaviour, and the ability to feel physical sensations) of people with Williams syndrome, Prader-Willi syndrome, and Fragile X syndrome. In this study, participants are tested, file information is requested, and questionnaires are completed.

We distribute the Pain Questionnaire in various Dutch and English countries. The purpose of the questionnaire is to gather experiences and knowledge about pain from people directly involved in adults with Williams, Prader-Willi, and Fragile X syndromes (such as family and Personal Support Workers). Sharing this information provides valuable insight and practical tools for dealing with pain. The person filling the questionnaire does not participate in the rest of the study.

The reason that we approach you is the request to distribute the Pain Questionnaire. If you choose to participate, then we will send you a link to send to your members. This could be by e-mail, newsletter, and/or a private Facebook group. If possible, only members involved in adults (18 years and older) with a syndrome will be selected. The members can then fill in the questionnaire, which will take on average 30 minutes.

Data will be collected anonymously and will therefore not require personal information such as name, gender, and date of birth. The questionnaire will be completed online.

We would like to hear from you whether we may continue to contact you about sending the Pain Questionnaire. If there are any questions, then please contact [postdocteam.fgb@vu.nl](mailto:postdocteam.fgb@vu.nl) or the principal investigator (see below).

Thank you for your cooperation!

Sincerely,

Researcher Nanda de Knegt

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