

Quality of life experience in patients with Niemann-Pick disease Type C during the COVID-19 pandemic- a qualitative approach

Hi everyone,

Are you an adult who has been diagnosed with Niemann-Pick disease type C (NPC) or the parent/caregiver of someone who has been diagnosed with NPC?

If so, we would like to invite you to take part in our research study looking at quality of life in those with NPC.

It will involve an interview via Microsoft Teams, Skype, Zoom or telephone where we ask you questions regarding quality-of-life experience and Niemann-Pick disease type C (NPC). We are particularly interested in the impact of diagnosis, treatment (if applicable) and the COVID-19 pandemic on the experience quality of life in Niemann-Pick disease patients. The interview should last no longer than one hour.

Please note: the interview will be conducted in English; therefore the study is open to those who are able to read and understand the study information sheets (written in English) and are able to give informed consent in English.

This study forms part of a PhD project conducted by Jackson Pountney, funded by Aston University and Niemann-Pick UK (NPUK), the International Niemann-Pick Disease Alliance (INPDA), the International Niemann-Pick Disease Registry (INPDR) and the National Niemann-Pick Disease Foundation (NNPDF). The study is looking at the impact of NPC on the quality of life in patients and carers. We are keen to understand the quality-of-life experience in NPC patients and those who care for them in order to help validate quality of life questionnaires for NPC patients, which will help accurately convey to others how NPC affects you in daily life.

If you are interested in taking part, please click here:

https://astonpsychology.eu.qualtrics.com/jfe/form/SV_9pltKHxmvKOZYNw to find out more about the study, and if you are interested in taking part there is a form for you to leave your name and contact details. I will then get in touch to arrange an interview.

If you would like to discuss the study please contact **Jackson Pountney** by email on 200216137@aston.ac.uk.

Many thanks,

Jackson Pountney

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