

Subject: International ketogenic diet registry – Please complete this survey!

Date: 10 November 2022 - 11:02:00 AM GMT

Dear ILAE members,

We are currently undertaking a project to set-up an international registry of individuals with epilepsy referred for ketogenic dietary therapy. This will act as a platform to investigate key research questions that are not yet fully answered, with the overall purpose of determining long-term clinical and safety outcomes and identifying the most suitable candidates for dietary treatment.

As the first part of this project, we are conducting a Delphi survey to gain consensus on which data should be included in the registry. We are asking the opinion of multidisciplinary healthcare professionals working with ketogenic diets internationally, and we would welcome your input. The survey can be accessed by the following link:

<https://app2.welphi.com/Pages/RedirectPage.aspx?eHYUn/srrCCXRaLDWfEnXW2giu9SD74r3ty9cdZco8N5g3ewXLQsObh1GCSfEQFA>

The link will prompt you to enter your email and a password, and then direct you to a set of questions. The survey should take no more than 15 minutes to complete, and all replies will remain anonymous. It will be open for six weeks and we would be grateful if you could complete it by **Friday 23rd December 2022**. If you are happy for us to do so, we will then contact you again in early 2023, using the email you previously entered, to partake in the second Delphi round.

Please pass the survey details on to other members of your ketogenic team (e.g. other neurologists, dietitians, ketogenic nurses and/or psychologists) as we are keen to hear from a range of different health professionals working with ketogenic diets.

More information on the registry project can also be found at the end of the survey.

With best wishes,

Dr Liz Neal

on behalf of the Ketogenic diet registry team: Dr Natasha Schoeler, Victoria Whiteley,
Dr Elles van der Louw