The IMPACT survey: Identifying the perspectives of patients diagnosed with primary membranoproliferative glomerulonephritis and/or parents of patients regarding potential participation in future clinical trials

Currently, there is no approved treatment for primary membranoproliferative glomerulonephritis diseases like MPGN, IC-MPGN, C3G, C3GN or DDD. Clinical trials are often the only opportunity for patients to access new drugs. Understanding how to design future clinical trials in ways that take into consideration the needs and concerns of patients and caregivers is important and can help improve trial outcomes.

Are you diagnosed with a primary membranoproliferative glomerulonephritis disease or are you a parent of a child with membranoproliferative glomerulonephritis? Take our online survey to let us know:

- What is it like to live with a primary membranoproliferative glomerulonephritis disease?
- What is important for you when considering participation in a clinical trial for you or your child?
- What kind of support do you need from researchers and health care professionals?

The survey is anonymous, available in 6 languages (English, Italian, Dutch, German, French, Norwegian), and takes approximately 20 minutes to complete:

http://www.era-decode.eu/survey.html

Your responses will help researchers design future clinical trials for MPGN.

The survey is part of the DECODE project aiming to identify new strategies to improve diagnosis, prognosis, and treatment of MPGN patients. The DECODE project is led by Professor Ariela Benigni at the Mario Negri Institute, Italy. The survey is organized in collaboration with Progetto DDD Onlus, the Dutch Kidney Patients Association, and the German association for rare complement-mediated diseases. General survey results will be available on the DECODE website in 2023.

To know more about DECODE: http://www.era-decode.eu/index.html

For any questions regarding the survey, please contact decode@fhi.no

Thank you!

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