

IRB-Approved Study Information Language for Participants:

Study Information Sheet – Person diagnosed with bvFTD Version

Study Title: Cognitive Interviews to Assess Content Validity of Questionnaires for Persons Affected by Behavioral-Variant Frontotemporal Dementia (bvFTD) and Their Informants

You are invited to participate in this research study because you were diagnosed with behavioral variant frontotemporal dementia (bvFTD). This research is being conducted by a company called ICON and sponsored by Biogen, a pharmaceutical company. The purpose of this research is to better understand the symptoms and daily life experiences associated with bvFTD, as well as the relevance and understanding of several questionnaires. This will allow Biogen to better understand the questionnaires and topics most relevant and important to you, to other people diagnosed with bvFTD and to their caregivers/informants.

You are being asked to participate in a 60-120 minutes in-person interview conducted by an experienced researcher. If you qualify and choose to participate, you will be paid **\$100** for completing the interview.

The information we gather from you will be kept separate from your medical records. Your participation in this study will not affect your treatment in any way, even if you decide not to be in the study or if you start the study and then change your mind. To protect your privacy, your name will not appear on any study materials or any publications that may result from this research.

If this sounds like something you would be interested in taking part in, or if you would like more information about this study, please contact ICON (information provided below) for further details.

Thank you!

ICON Research Team

Contact information:

Joanna Rodriguez joanna@global-perspectives.eu

Guiomar Gonzalez guiomar@global-perspectives.eu