

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

Study Information Sheet – Informant Version

You are invited to participate in this research study because you are a spouse/ partner/ friend/ caregiver/ informant of someone who was 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 from a caregiver/ informant perspective, 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 and other caregivers/ informants of people diagnosed with bvFTD.

You are being asked to participate in a 90-120 minute, one-time interview conducted by an experienced researcher. If you qualify and choose to participate, you will be paid **\$150** for completing the interview.

The information we gather from you will be kept separate from the person diagnosed with bvFTD's medical records. Your participation in this study will not affect your and the person diagnosed with bvFTD you know's 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, no names will 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