



Institute for the Co-production of Knowledge about Huntington's Disease

Abstract for EHDN plenary Meeting, 14-16th of September, 2012.

Title:

Being huntingtonian – a multidisciplinary experiment of creation of knowledge about HD.

Abstract:

The main objective of “Dingdingdong – Institute for the Co-Production of Knowledge about HD” is to create knowledge about HD, which takes into consideration the expertise, produced by sick persons, carriers at risk, families, as well as by physicians.

How shall we proceed in order to avoid the usual exclusion of patients from the knowledge which is built about them? This methodological and epistemological issue guides the research undertaken by our multidisciplinary and independent team, composed by users, researchers in social sciences, artists, and physicians. Dingdingdong is a platform of thought, creation and innovation about how to elaborate a constructivist (and constructive) approach of disease. We especially concentrate on testimonies or what might be called HD-stories.

The poster will present the different stakes of this project founded in 2012: its methodology, multidisciplinary team, needs in terms of testimonies, first results and perspectives.

Key words:

illness ethnography ; users' testimonies ; care studies ; pragmatic philosophy ; ...

Authors:

Emilie Hermant (1), Valérie Pihet (2), Katrin Solhdju (3)

(1) Dingdingdong, Institute for the Co-Production of Knowledge about HD, 23 rue des Fêtes, 75019 Paris, France

(2) Sciences Po Paris, 27 rue Saint Guillaume, 75007 Paris France

(3) Center for Literary and Cultural Research, Schützenstr. 18, 10117 Berlin, Germany