

# Inherited Disease, Caregiving, and Social Networks

<https://www.neurodegenerationresearch.eu/survey/inherited-disease-caregiving-and-social-networks/>

## Principal Investigators

KOEHLI, LAURA

## Institution

National Human Genome Research Institute

## Contact information of lead PI

### Country

USA

## Title of project or programme

Inherited Disease, Caregiving, and Social Networks

## Source of funding information

NIH (NIA)

## Total sum awarded (Euro)

€ 642,410.09

## Start date of award

## Total duration of award in years

2

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

Acquired Cognitive Impairment... Aging... Alzheimer's Disease... Alzheimer's Disease including Alzheimer's Disease Related Dementias (AD/ADRD)... Basic Behavioral and Social Science... Behavioral and Social Science... Brain Disorders... Caregiving Research... Clinical Research... Clinical Research - Intramural... Dementia... Genetics... Human Genome... Neurodegenerative

## Research Abstract

In collaboration with Dr. Sato Ashida at the University of Iowa, we completed a pilot study examining caregiving networks of families affected by Alzheimers disease and related dementia

(ADRD). The goal was to pilot an assessment tool we developed to uncover the Caregiving Roles and Expectations within informal caregiving Networks (or CaRENet). Index participants were recruited from four dementia care facilities and snowball sampling was used to recruit family members. A total of 73 family caregivers from 30 families answered interview questions regarding their social networks systems, cognitions and emotions about the disease and caregiving, well-being, and socio-demographic characteristics. Additionally, patient information was obtained from 43 formal care providers. From this pilot study, we have shown the value of a multi-informant approach to capture the structure and composition of the caregiving network system that surrounds those affected by ADRD. Further, we have shown that social relationships are both stressors and coping resources which have significant influence on caregiver well-being. This work has resulted in one publication and two manuscripts that are currently under review. We have expanded our inquiry to consider how such caregiving experiences might differ according to the life stage, disease context, and disease stage faced by each caregiver and care recipient. As such, we are partnering with colleagues who have established patient cohorts in the NIH Clinical Center, including the Undiagnosed Diseases Program and patients with inborn errors of metabolism and mitochondrial disease. In each, patients require significant caregiving resources related to activities of daily living. Those enrolled in this research complete a survey and interview; primary caregivers who visit the NIH Clinical Center are also asked to provide samples for biomarker assessment. During the current reporting period, we have begun recruitment of caregivers and family members for this new research. To that end, we have successfully consented 63 individuals from 38 families involved in caregiving networks.

### **Lay Summary**

**Further information available at:**

#### **Types:**

Investments > €500k

#### **Member States:**

United States of America

#### **Diseases:**

Alzheimer's disease & other dementias

#### **Years:**

2016

#### **Database Categories:**

N/A

#### **Database Tags:**

N/A