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## Synchronizing Oneself with Science

### How Individuals with Parkinson's Disease Go Along with Clinical Trials

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Presentation title:

## **Synchronizing Oneself with Science:**

How Individuals with Parkinson's Disease Go Along with Clinical Trials

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Abstract:

Sweden has a long tradition when it comes to biomedical research on Parkinson's disease. For example in the 1980s the first neuron cell transplantation to a Parkinson patient in the world took place in Sweden. Today Swedish Parkinson scientists, in collaboration with researchers in other countries, continue the search for a cure for Parkinson's disease within several research fields.

In the last years I have followed a biomedical research project in Sweden focused on realizing clinical trials with Parkinson patients within the field of cell transplantation. In my work I have conducted interviews with patients, researchers and medical staff as well as observations in hospital environments and in contacts with patient's organizations.

My aim with this presentation is to explore what constitutes a clinical trial from the viewpoint of the patients. How does this biomedical research matter for trial-participating as well non-participating patients? How does one as patient follow and understand the clinical trials? How does one move along in relation to what one, on the basis of one's degenerative illness, perceives as the progress of science? Individuals with Parkinson are, in this sense, temporal beings in whatever they do or calculate in relation to science. Taking part in clinical trials is viewed as a way of synchronizing one's self with what one experiences as the tempo of practiced science. In my presentation I will explore different concepts for how a form of time sensitivity can be studied among patients.

Keywords: synchronizing, Parkinson's disease, clinical trials, participation, time, patient perspective