

ICREA CONFERENCE

# Personhood and the Locked-In Syndrome

The locked-in syndrome (LIS), in which persons are conscious but almost entirely paralyzed and voiceless, is one of the most dramatic states a human being can find himself or herself in. This interdisciplinary international workshop will bring together cognitive neuroscientists, care and neuro-rehabilitation professionals, brain-computer interface experts, individuals involved in LIS patients associations, philosophers, bioethicists, medical anthropologists and sociologists, and historians of the brain/mind sciences to discuss the impact this unique condition has on ways of understanding personhood at the theoretical and practical levels.

While the philosophy of personhood in the Western tradition since the late 17th century has emphasized cognitive capacities and self-consciousness, the experience of LIS contributes to open new ground for understanding how relationality, emotion, communication and phenomenal consciousness (the feeling of what it is like to be in a certain state) are constitutive of personal identity and the sense of self.

17 and 18 November 2016

Sala de Juntas, Facultat de Filosofia y Letras,  
Autonomous University of Barcelona



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### PROGRAM

#### THURSDAY 17 NOVEMBER

10:00-10:45 h

**Welcome. Organization and Introduction,** Fernando Vidal and Núria Terribas

10:45-11:00 h **Break**

11:00-11:30 h

**The Self and the Person: A Distinction of Relevance for Patients with Locked-In Syndrome?,** Dan Zahavi

11:30-12:00 h

**Being Alive: An Enactive Approach to the Self,** Miriam Kyselo

12:00-12:30 h **Discussion**

13:00-14:30 h **Lunch**

14:30-15:00 h

**Reconstructing and Realizing a Life Project in LIS: Conditions and Limits,** Véronique Blandin

15:00-15:30 h

**Living with a Ventilator: A Japanese Perspective,** Yumiko Kawaguchi

15:30-16:00 h **Discussion**

16:00-16:15 h **Break**

16:15-16:45 h

**The History of BCI (Brain-Computer Interface): From a Vision to Independent Home Use by Locked-in Patients,** Andrea Kübler

16:45-17:15 h

**BCI for Communication in Locked-in Syndromes: What is Needed to Match Users and Technology,** Donatella Mattia & Febo Cincotti

17:15-17:30 h **Break**

17:30-18:00 h **Discussion**

#### FRIDAY 18 NOVEMBER

10:00-10:30 h

**Locked-in Patients/Locked-out Doctors: A History of Persistent States of Being There,** Stephen Casper

10:30-11:00 h

**The Locked-in State as a Final Stage of Individuation: A Phenomenological and Qualitative Analysis of a Caregiver's Narrative,** Yasuhiko Murakami

11:00-11:30 h **Discussion**

11:30-11:45 h **Break**

11:45-12:15 h

**Which Factors Foster Resilience in the LIS?,** Marie-Christine Nizzi

12:15-12:45 h

**Being Locked-In and the Paradox of Disability,** Bernabé Robles del Olmo

12:45-13:15 h **Discussion**

13:30-15:00 h **Lunch**

15:00-15:30 h

**The Body, Personal Identity, and Social Integration in Locked-in Syndrome Patients,** Nicole Beaudoin

15:30-16:00 h

**Life at Home Years After Hospital Discharge: “Bed of Roses” or “Rebel Without a cause”?** An Analysis of Breakdown Situations at Home, Frédéric Pellas

16:00-16:30 h **Discussion**

16:30-16:45 h **Break**

16:45-17:15 h

**Neuroethical Implications of Clinician's Attitudes Toward the Locked-in Syndrome,** Athena Demertzi

17:15-17:45 h

**Medical Decision Making by Patients with Locked-In Syndrome,** James L. Bernat

17:45-18:00 h **Break**

18:00-18:30 h **Discussion + Closing**

# Personhood and the Locked-In Syndrome

## LIST OF SPEAKERS

### COORDINATOR:

**Fernando Vidal.** Research Professor, ICREA (Catalan Institution for Research and Advanced Studies); Professor, CEHIC (Center for the History of Science, Universitat Autònoma de Barcelona), Spain.

With the collaboration of:

**Núria Terribas.** Executive Director, Víctor Grífols i Lucas Foundation, Barcelona, Spain.

### SPEAKERS:

**Nicole Beaudoin.** Head of the Department of Rehabilitation Medicine, Institut Gingras-Lindsay de Montréal, Montreal, Canada.

**James L. Bernat.** Louis and Ruth Frank Professor of Neuroscience, Geisel School of Medicine, Dartmouth College, Lebanon, NH, United States.

**Véronique Blandin.** Déléguée générale, ALIS (Association du Locked-in Syndrome), France.

**Stephen Casper.** Associate Professor of History, Clarkson University, Department

of Humanities and Social Sciences, Potsdam, NY, United States.

**Febo Cincotti.** Department of Computer, Control, and Management Engineering, Sapienza University of Rome, Italy.

**Athena Demertzi.** Post-doctoral fellow, Institut du Cerveau et de la Moelle Épineuse, Paris, France.

**Yumiko Kawaguchi.** Director, Japan ALS Association; Founder and director, ALS/MND Support Centre Sakura, Japan.

**Andrea Kübler.** Professor, Department of Psychology, University of Würzburg, Germany.

**Miriam Kyselo.** Marie Curie Postdoctoral Fellow, Berlin Center for Knowledge Research, Technical University, Berlin, Germany.

**Donatella Mattia.** Neuroelectrical Imaging and BCI Lab, Fondazione Santa Lucia, IRCCS, Rome, Italy.

**Yasuhiko Murakami.** Professor of Philosophy, Graduate School of Human Science, Osaka University, Japan.

**Marie-Christine Nizzi.** Department of Psychology, Harvard University, Cambridge, MA, United States.

**Frédéric Pellas.** Post-intensive Care Rehabilitation Unit, Hôpital Universitaire, Nîmes, France.

**Bernabé Robles del Olmo.** Head of the Neurology Unit, Parc Sanitari Sant Joan de Déu, Barcelona, Spain.

**Dan Zahavi.** Professor, Center for Subjectivity Research, University of Copenhagen, Denmark.

