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Questioned Consciousness in the Memoirs of Jean-Dominique Bauby, Julia Tavalaro, and Philippe Vigand: Unlocking and Teaching the Locked-In Writings of the Written Off

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QUESTIONED CONSCIOUSNESS IN THE MEMOIRS OF JEAN-DOMINIQUE BAUBY, JULIA TAVALARO, AND PHILIPPE VIGAND: UNLOCKING AND TEACHING THE LOCKED-IN WRITINGS OF THE WRITTEN OFF

A Dissertation

Submitted to the School of Graduate Studies and Research

in Partial Fulfillment of the

Requirements for the Degree

Doctor of Philosophy

Henry C. Stewart

Indiana University of Pennsylvania

May 2012

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We hereby approve the dissertation of

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Christopher M. Kuipers, Ph.D. Assistant Professor of English

ACCEPTED

Timothy P. Mack, Ph.D. Dean The School of Graduate Studies and Research Title: Questioned Consciousness in the Memoirs of Jean-Dominique Bauby, Julia Tavalaro, and Philippe Vigand: Unlocking and Teaching the Locked-In Writings of the Written Off Author: Henry C. Stewart Dissertation Chair: Dr. James M. Cahalan Dissertation Committee Members: Dr. Susan Comfort Dr. Christopher M. Kuipers

Jean-Dominique Bauby, Julia Tavalaro, and Philippe Vigand each composed hauntingly beautiful memoirs—*The Diving Bell and the Butterfly, Look up for Yes*, and *Only the Eyes Say Yes*, respectively—after being afflicted with locked-in syndrome following strokes. They were also each at one point considered completely vegetative and unaware of themselves or their surroundings. This very unique perspective, what Bauby calls "the harsh light of disaster," distinctively situates them in the field of literary studies. With this study, I seek to remedy the existing lack of scholarly attention to these memoirists and their works and consider their place in literary canons; also, I strive to determine and record potential commonalities that exist in these autobiographical texts and in these individuals for the purpose of contributing a subfield that focuses on individuals whose consciousness has been questioned to the burgeoning field of literary disability studies; and, ultimately, I hope to construct a pedagogical resource for literary practitioners interested in teaching the quite remarkable works of Bauby, Tavalaro, and Vigand.

While my focus is on locked-in syndrome, more and less severely acquired and traumatically brain-injured individuals are often misunderstood at best and outright neglected at worst. Sometimes, one need not even be brain-injured for one's consciousness to be questioned. For these reasons, I also secondarily examine Shakespeare's *Othello* under the lens of a potential brain injury, Frederick Douglass's autobiographical writings as an example of an individual whose consciousness is questioned but does not suffer from a brain injury, and Dalton Trumbo's *Johnny Got His Gun* as an example of a fictional character in a similar situation as Bauby,

Tavalaro, and Vigand. The commonalities in each of these individuals are that each consciousness was questioned (albeit in very different ways), each was treated as somehow less than human as a result, and that treatment influenced their thoughts, actions, and, in the case of Bauby, Tavalaro, and Vigand, their writings.