

# *THE RARE DISEASES CLINICAL RESEARCH NETWORK AS A NESTED CULTURAL COMMONS*

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Concerns about the productivity of the pharmaceutical industry, the accessibility of treatment, and the expense of healthcare have led to numerous experiments with “openness” at various stages of research. One issue of particular concern is the difficulty in applying the current “blockbuster drug” model to rare diseases and conditions. The Rare Diseases Clinical Research Network (“RDCRN”) is an attempt by the United States government to overcome some of these difficulties and to foster a collaborative approach to rare disease clinical research and treatment development, essentially by constructing a commons. The basic idea behind the RDCRN is to construct a network of research consortia, with the dual aims of improving understanding of the disorders, improving diagnostics, and developing better treatments for the particular disorders represented by the funded consortia and developing infrastructure and clinical research methodology that may be used more broadly in studying rare diseases. This project will apply the constructed cultural commons framework (Madison, Frischmann & Strandburg 2010) to study the RDCRN and related patient advocacy groups. In this paper, we begin by focusing on the structure of the RDCRN itself and on one specific consortium that has been part of the RDCRN since the beginning in 2003 – the Urea Cycle Disorders Consortium (UCDC). To date, we have conducted a literature review, using the cultural commons framework to structure our observations, which we present below. We also will present the results of some interviews, which are currently underway.