

## **The HHS Refusal Rule and Biomedical Research: What Biomedical Research Advocates Should Know About the HHS Rule**

On December 18, 2008, the Department of Health and Human Services (HHS) issued a final rule that in addition to posing a serious threat to women's health, significantly limits *all* patients' access to health care and important information about their health care options. This rule has serious implications for biomedical research activities at academic, nonprofit, and corporate research institutions that receive federal funds.

The following are some facts that every biomedical research advocate should know about the HHS rule:

### **What Is The HHS Refusal Rule?**

The HHS Refusal Rule radically rewrites laws, some of which have been on the books for over 30 years. HHS claims that it is merely educating recipients of HHS funds about their legal obligations under three federal laws: the Church Amendments, the Weldon Amendment, and the Coats Amendment. These laws give individuals and institutions the ability to refuse to provide, or prohibit requiring the performance of or participation in, abortion or sterilization services. Yet, the HHS rule dramatically expands the scope and reach of these laws beyond abortion or sterilization care. The rule prohibits entities from requiring individuals to assist in the performance of “*any* part of a health service program or *research activity* funded by the Department if such service or activity would be contrary to his religious beliefs or moral convictions” (emphasis added). This means that the rule is so broad that it allows researchers, laboratory assistants, doctors, nurses, and nearly any employee in a health care or research setting receiving funds from HHS to refuse to participate in nearly any research activity or provide care to any individual receiving any service – if doing so would violate his or her moral beliefs – without regard for the needs of patients or research programs.

### **How Does The HHS Rule Impact Biomedical Research?**

The HHS Refusal Rule prohibits a wide array of HHS-funded entities, including laboratories, universities, think tanks, and post-graduate physician training programs and hospitals, from discriminating against any personnel who refuse to perform, or assist in, *any* research activity or service. This rule could adversely affect a broad range of research efforts, including federally-funded stem cell research, research involving animal testing, and research intended to help protect U.S. soldiers from biological weapons. For example,

- A nurse working at an academic medical center receiving funding from the National Institutes of Health could refuse to administer an experimental treatment derived from research which used embryonic stem cells to a spinal cord injury patient because the nurse has a moral objection to embryonic stem cell research.
- A laboratory assistant working in an academic medical center that receives federal HHS funds may refuse to participate in research involving animal testing on the grounds that doing so would violate his or her moral beliefs.

### What Else Is Wrong With The HHS Refusal Rule?

- **The final rule threatens to undermine employers' ability to protect patients or research programs while also respecting employees' religious beliefs.** For more than four decades, Title VII of the Civil Rights Act of 1964 has provided a balance of interests, giving employers leeway to take into account the effect of an employee's refusal on a patient's health care need. The final rule undermines this carefully crafted balance between the right of individuals to enjoy reasonable accommodation of their religious beliefs and the right of employers to conduct their business without undue interference.
- **The final rule fails to protect patients even in emergency situations.** The rule does not adequately address employers' legal obligations to provide medical care in the case of an emergency. This failure could place patients in need of emergency medical care in grave danger and expose them to serious harm.
- **The final rule undermines patients' access to basic information about their health and treatment options.** The rule even allows providers to withhold basic information from patients about their health care options – threatening the health, safety, and autonomy of all patients.

### What Can Biomedical Research Advocates Do?

- Learn more about the HHS rule by visiting our website: <http://www.nwlc.org/hhsrule>.
- Urge President-Elect Barack Obama to reject this harmful rule immediately upon entering office by taking action: <http://action.nwlc.org/hhsruleaction>.
- Call the National Women's Law Center at (202) 588-5180 if you have any questions or need additional information.

*January 2009*