

NEWS RELEASE

Office of Communications
Media Contact: Ralph Loglisci
410-516-8523; RalphL@jhu.edu

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(Baltimore) The Greenwall Foundation recently awarded two core faculty members of the Johns Hopkins Berman Institute of Bioethics a grant that will allow Drs. Gail Geller and Cynda Hylton Rushton to explore the ethical challenges health professionals face while caring for children and families affected by life-threatening neuromuscular diseases (LTNMD).

The concept for this latest LTNMD study grew out of the work of the international HeartSongs Project funded by the Stavros Niarchos Foundation. The goal of the HeartSongs Project is to develop a worldwide network of professionals from a range of disciplines, parents and affected children who share a common vision of comprehensive care for children with LTNMD. In addition to the United States, countries involved in the HeartSongs project include the United Kingdom, Canada, Australia, France, Denmark and Greece. The Project aims to integrate the principles of pediatric palliative care (PPC) into the care of individuals living with LTNMDs. PPC can be described as a holistic, interdisciplinary model of care that incorporates emotional, spiritual, developmental, and physical dimensions. The HeartSongs' International Consortium will develop recommendations regarding promising practices in comprehensive and integrated care. The two-year project, co-directed by Geller and Rushton, opened with a summit in England this past April and will culminate in a second summit to be held in Greece in March 2009. Hopes for a HeartSongs II call for expanding the project to include more European countries as well as countries in South America, Africa, Asia and the Middle East.

The HeartSongs Project is named in honor of the young American poet Mattie J.T. Stepanek who lived with a rare form of muscular dystrophy. Mattie's messages of love, hope and peace have stirred the hearts and souls of millions worldwide. The author of 7 books, Mattie shared hope through his 'HeartSongs' poetry, and collaborated with Former President Jimmy Carter on an essay book, *Just Peace*. (<http://www.mattieonline.com/>) Mattie died in 2004 just before his fourteenth birthday. According to Dr. Rushton, "Mattie's legacy for a better world for all children has inspired our work to improve the lives of children, like Mattie, who live with LTNMDs."

Geller and Rushton's earlier research, also funded by the Stavros Niarchos Foundation, revealed that many parents of children living with LTNMD often do not take advantage of Advanced Care Planning (ACP) as early as experts recommend. "Because the life expectancy of LTNMDs is

uncertain and unpredictable,” Drs. Geller and Rushton claim that “ACP, and palliative care more broadly, should not be restricted solely to children who are considered close to death.”

Geller and Rushton’s newest Greenwall Foundation funded study will focus on the attitudes and behaviors of health professionals who care for patients living with Duchenne Muscular Dystrophy (DMD) and Spinal Muscular Atrophy (SMA Type 1), the two most common pediatric LTNMDs worldwide. “Although both diseases are life threatening,” says Dr. Geller, “each has a unique life expectancy and disease trajectory thereby creating distinct ethical challenges for the children, their families and the health care team.” Dr. Rushton says, “based on a review of the literature and our own prior work, there is a need to more fully understand the nature, prevalence, and consequences of ethical challenges experienced by Neuromuscular Disease specialists who care for these children, adolescents and their families.” These findings will fill an important gap that will inform the development of targeted interventions to support patient/family centered care of children with LTNMD’s and their families.

Rushton and Geller say results of the national survey of health care practitioners will be presented to a focus group of regional Muscular Dystrophy Association-clinic directors and pediatric palliative care specialists to develop clinical and policy recommendations for enhancing ethically appropriate care for children with LTNMD.

Most of Drs. Rushton and Geller’s research and work is motivated by their commitment to improving the quality of life for patients and families, involving patients and families in communication and decision-making, and improving communication and well-being among interdisciplinary health professionals. In addition to her work at the Berman Institute, Gail Geller, ScD, MHS is a professor at the School of Medicine with joint appointments in the Department of Pediatrics and the Bloomberg School of Public Health’s departments of Health, Behavior & Society and Health Policy & Management. In addition to her affiliation with the Berman Institute, Cynda Hylton Rushton, PhD, RN is the program Director of the Harriet Lane Compassionate Care Program at The Johns Hopkins Children's Center, and an associate professor at the School of Nursing. She is a Robert Wood Johnson Executive Nurse Fellow.

About the Johns Hopkins Berman Institute of Bioethics

One of the largest centers of its kind in the world, the Johns Hopkins Berman Institute of Bioethics is the home for collaborative scholarship and teaching on the ethics of clinical practice, public health, and biomedical science at Johns Hopkins University. Since 1995, the Institute has worked with governmental agencies, non-governmental organizations, and private sector organizations to address and resolve ethical issues. Institute faculty represent such disciplines as medicine, nursing, law, philosophy, public health, and the social sciences. Their works helps anticipate and inform debates on complex moral challenges; discerns ethically acceptable alternatives in medical, scientific, and public health policy; and helps to prepare the next generation of bioethicists. More information is available at www.bioethicsinstitute.org.

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