

### NIH Extends \$1 Million Grant for Pediatric Palliative Care Initiative

November 3, 2009 — An initiative to build empathy and understanding among medical professionals who treat pediatric palliative care patients has been awarded a \$1 million, two-year grant from the National Institutes of Health National Institute for Nursing Research (NINR).

Co-directed by Cynda Rushton, PhD, RN, FAAN, associate professor at the Johns Hopkins University School of Nursing (JHUSON), the study was one of only four percent that NIH funded among 20,000 Challenge Grant applications filed nationally. Seventeen other NIH Challenge Grants were extended to JHU schools.

With the grant, Rushton – who holds a joint faculty position with the Johns Hopkins University School of Medicine and serves as director of Johns Hopkins Children’s Center’s Harriet Lane Compassionate Care program –will develop new training videotapes, and expand existing ones, that are geared toward improving palliative care. The project team also includes co-director Gail Geller, ScD, MHS; Mary Catherine Beach, MD, MPH; and Carlton Haywood, PhD, MA.

The effort, to be jointly run with the university’s Berman Institute of Bioethics where all four researchers are faculty members, is meant to sensitize the entire health care team that treats pediatric patients with either Duchenne muscular dystrophy (DMD) or sickle cell disease (SCD).

DMD and SCD are among the most common chronic, inherited, life-threatening diseases. But palliative care (defined as alleviating a patient’s symptoms, regardless of whether the condition is curable) ultimately can improve the overall care DMD and SCD patients receive, Rushton and Geller said.

The researchers believe that the project will make caregivers— including neurologists, hematologists and other physicians; nurses; respiratory, occupational and physical therapists; genetic counselors; and social workers — “more compassionate and respectful, with a better understanding of what their [patients’] lives are like,” Rushton said. They will address caregivers’ emotions in treating such patients — the “tremendous feeling of inadequacy because of not being able to fix [what] is not fixable,” Geller added.

“Palliative care generally has been associated with end-of-life care,” Geller added. “This is the first study to remove palliative care from [that] limited context and to say, ‘What can we learn from the principles of pediatric palliative care in the context of chronic diseases?’ ”

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