

Continuing Education Offering on Wednesday, April 6 OR Thursday, April 7

A Vision of Hope: Integration of Palliative Care in Chronic Pediatric Disease~ Duchenne Muscular Dystrophy and Sickle Cell Disease

PROGRAM DESCRIPTION

The absence of a cure can breed despair and loss of hope. This educational opportunity is designed to improve the quality of care, and instill a new vision of hope, for adolescents, young adults and families affected by chronic, life-threatening diseases by integrating the principles and practices of palliative care into the training of the clinicians who care for them.

The focus is on two of the most common, chronic, genetic diseases: Duchenne Muscular Dystrophy and Sickle Cell Disease. Although improved technologic and medical interventions have significantly increased the life expectancy of affected individuals, new challenges have been created with regard to transitioning patients from pediatric to adult care clinicians and settings.

Palliative care offers a comprehensive, holistic model for designing transitional systems by anticipating these transitions as part of advance care planning, preparing for autonomous, patient focused decision making, and learning how to advocate for symptom management, pain relief, and access to services to support quality of life within the health care system.

The 90 minute in-service will provide an opportunity for clinicians to begin to explore the lived experiences and unmet needs of adolescents and young adults with these chronic, life-threatening diseases, and the impact of caring for these populations on interdisciplinary teams of clinicians, directly from the patients, parents and clinicians, themselves, through several short video documentaries. Clinicians from all disciplines will have an opportunity to explore the relevant themes illuminated in these films and recognize how the integration of palliative care principles and practices in to their own practice can positively impact quality of life.

SPEAKERS:

Gail Geller, Sc.D., M.H.S., is a Professor in the Department 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. She has a primary affiliation in the Berman Institute of Bioethics, where she is Co-Deputy Director of the Greenwall Post-doctoral Fellowship Program in Bioethics & Health Policy. She also has an affiliation in the McKusick-Nathans Institute of Genetic Medicine and the Johns Hopkins/NHGRI master's program in genetic counseling. She received her B.S. from Cornell University and her doctorate from the Johns Hopkins School of Public Health with concentrations in bioethics and social and behavioral sciences.

Cynda Hylton Rushton, PhD, RN, FAAN is an associate professor of nursing, with a joint appointment in the Johns Hopkins University School of Medicine's Department of Pediatrics. Dr. Rushton is a core faculty of the Johns Hopkins Berman Institute of Bioethics and co-chair of the Johns Hopkins Hospital's Ethics Consultation Service. She also serves as a Clinical Nurse Specialist in Ethics and Program Director of the Harriet Lane Compassionate Care Program at The Johns Hopkins Children's Center. She received her master's of science in nursing, with specialization as a pediatric clinical nurse specialist, from the Medical University of South Carolina. She completed her

undergraduate degree in nursing at the University of Kentucky and received a doctorate in nursing at the Catholic University of America, with a concentration in bioethics. Dr. Rushton is the recipient of two post-doctoral fellowships: a Robert Wood Johnson Nurse Executive Fellowship (2006-2009) and a Kornfeld Fellowship in end-of-life, ethics and palliative care (2000).

NO FEE: In-service provided by NIH Challenge Grant

PROGRAM OBJECTIVES

Using videos/discussion, the participants will:

1. Discuss the lived experiences and unmet needs of adolescents and young adults with these chronic, life-threatening diseases.
2. Explore the impact of caring for these populations on interdisciplinary teams of clinicians.
3. Recognize how the integration of palliative care principles and practices can positively impact quality of life.

GENERAL INFORMATION: For additional information contact: Janet Pniewski, RN, BSN, Project Coordinator, Johns Hopkins University, Berman Institute of Bioethics, 540-272-7100 or email pniewsk@jhsph.edu. For CCHMC questions, email Sharon Herndon or Anne Longo.

SESSION TIMES/LOCATION: Cincinnati Children's Medical Center

Wednesday, April 6, 2011

Duchenne Muscular Dystrophy Sessions: 11:30am in S1.203 or 6:00pm in D2.27

Sickle Cell Disease Sessions: 2:00pm in S1.203 or 8:00pm in D2.27

Thursday, April 7, 2011

Duchenne Muscular Dystrophy Session: 7:30am in S1.203

SCD Session: 9:30am in S1.203

REGISTER ONLINE is Preferred - WALK-INS ALSO WELCOME

Register online! at: www.cincinnatichildrens.org/cc and Click on the calendar.

Deadline: March 30, 2011 Please reserve your spot early, seating is limited.

AUDIENCE

The program is open to all clinicians (MD, RN, APN, RT, PT, OT, RD, SW, etc.) who care for adolescents and young adults with chronic, life-limiting illnesses such as Neuromuscular Disease and Sickle Cell Disease and their families. Community health care providers, hospice and palliative care, social work, bereavement counselors and spiritual care providers are also welcome.

CONTACT HOURS

Nursing: 1.5 contact hours will be awarded to nurses who attend the entire program and complete an evaluation tool. Cincinnati Children's Hospital Medical Center (OH-046/9-1-11) is an approved provider of continuing nursing education by the Ohio Nurses Association. (OBN-001-91), an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

Physicians: Cincinnati Children's Hospital Medical Center is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians. This activity has been approved for AMA PRA Category 1 Credit(s) TM.