New Web-Based Intervention To Help Families Of Children Recovering From A Bone Marrow Or Blood Stem Cell Transplant

[August 21, 2006] The National Cancer Institute has just announced funding of a five-year grant to develop and study a web-based intervention to help families of children who receive a bone marrow, cord blood or blood stem cell transplant. Dr. Susan Parsons, Director of the Center on Child and Family Outcomes at the Institute of Clinical Research and Health Policy Studies, Tufts-New England Medical Center, is the Principal Investigator with collaborators from the University of Wisconsin and the Blood & Marrow Transplant Information Network (BMT InfoNet).

According to Dr. Parsons, hematopoietic stem cell transplantation (HSCT), which includes bone marrow, peripheral blood stem cell and cord blood cells and is used as the treatment of a variety of malignancies and bone marrow failure disorders. During the transplant recovery process, care shifts back from the transplant center to the the child's home and local treatment center with the parents assuming the primary responsibility for coordinating the child's care. Traditional hospital-based interventions have focused on the peri-transplant period, but given the prolonged and demanding period of recovery (6-12 months), alternative interventions are needed.

To address these issues, investigators at Tufts-NEMC are collaborating with co-investigators at University of Wisconsin and the BMT InfoNet to develop a transplant-specific web-based intervention, HSCT-CHESS. This program will be adapted from the well-established University of Wisconsin Program, the Comprehensive Health Enhancement Support System (CHESS), using editorial contributions from BMT InfoNet. This module will be an interactive, web-based, health information and support system for pediatric HSCT parents and families.

According to Dave Gustafson, PhD, CHESS developer and co-investigator, "I am very excited to work with Dr. Parsons and the Tufts-NEMC and the BMT InfoNet teams on this project. The families of children going through bone marrow transplant desperately need information and support to deal with the incredible stresses caused by these treatments (and the diseases that underlie them). It will be a privilege to design and test support systems that have the potential to make a difference in their lives."

Susan Stewart, Executive Director of BMT InfoNet and co-investigator, added "when families are thrust into the world of transplantation, it is often hard to get answers to questions in a timely manner. This study will test an innovative strategy to help families keep on top of the mountain of information they must manage during transplant, and access the many support services they need."

Through a randomized controlled trial of 190 parents at four pediatric HSCT centers across the US beginning in June 2007, this study will evaluate the impact on health-related quality of life (HRQL) of HSCT-CHESS, comparing it to standard care over a six-month intervention period. Information about the impact of pediatric HSCT on the family will also be collected over the same time period. The four clinical sites will include City of Hope, Duarte, CA, Dana-Farber Cancer Center, Boston, MA, Fred Hutchinson Cancer Research Center, Seattle, WA, and Midwest Children’s Cancer Center, Milwaukee, WI

About Tufts-NEMC:

The Center on Child and Family Outcomes in the Institute of Clinical Research and Health Policy Studies at Tufts-New England Medical Center, under the direction of Susan K. Parsons, MD, MRP, is dedicated to advancing the development and application of knowledge regarding the quality of life of families experiencing chronic illness, with an emphasis on cancer. The Institute for Clinical Research and Health Policy Studies at Tufts-New England Medical Center
encompasses programs in clinical and health policy research, training programs in clinical research, and general resources for conducting clinical research.

**About BMT InfoNet:**

Blood & Marrow Transplant Information Network is a not-for-profit organization dedicated exclusively to serving the needs of persons facing a bone marrow, blood stem cell or umbilical cord blood transplant. Founded in 1990 by bone marrow transplant survivor Susan Stewart, BMT InfoNet strives to provide high quality medical information in easy-to-understand language, so that patients can be active, knowledgeable participants in their health care planning and treatment.

**About CHESS:**

The Comprehensive Health Enhancement Support System (CHESS(tm)) is a computer-based system of integrated services designed to help individuals cope with a health crisis or medical concern. CHESS was originally part of the Center for Health Systems Research and Analysis (CHSRA), both of which were founded by David H. Gustafson, Ph.D. CHSRA was formed in 1973 as a collaborative effort between the departments of Industrial Engineering and Preventive Medicine at the University of Wisconsin-Madison. CHSRA's interdisciplinary staff leads research and development of interactive health communication technologies in partnership with other organizations, in order to optimize individuals' health behaviors, quality of life, and use of resources. As a result of the tremendous growth of the CHESS projects it now it's own center.

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