



ASSOCIATION of PEDIATRIC  
HEMATOLOGY/ONCOLOGY NURSES

**FOR IMMEDIATE RELEASE**

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## **ADVANCES REPORTED IN TRANSITIONING PEDIATRIC SICKLE CELL DISEASE PATIENTS TO ADULT PROVIDERS**

### ***Increasing survival rates raise concerns over continuing care***

GLENVIEW, IL – Forty years ago, children born with sickle cell disease (SCD) were not expected to live past their teenage years. Today, medical advances are allowing children to live well into adulthood, raising concerns over who is going to care for these patients as adults. However, programs are underway to address these concerns, as reported in the March/April edition of *Journal of Pediatric Oncology Nursing*, published by the Association of Pediatric Hematology/Oncology Nurses (APHON).

Sickle cell disease is the most common genetic disorder among African Americans. One in 500 African-American newborns has the blood disease, but life expectancy has risen from age 14 in 1973 to around 50 today.

Donna M. Doulton, BSN, RN, is the Project Coordinator of the Regional Children's Sickle Cell Center, part of CHRISTUS Santa Rosa Children's Hospital (CSRCH) and the University of Texas Health Science Center in San Antonio (UTHSCSA). It is a comprehensive program providing services to children and adolescents with SCD and their families. Doulton writes that the center has developed a two-part transition program to care for their pediatric patients as they reach adulthood.

“We have transitioned 20 of our 18- to 27-year-old patients to adult providers recognizing that early preparation is essential. At the newborn's initial visit or transfer from another clinic the transition program is explained to the family. At age 13 years, all our patients are given a ‘Preparation for Transition’ binder. This binder is reviewed in detail with the patient and parent on a regular basis. At 18 years of age, coordinating with the milestone of graduating from high school and depending on developmental age, the transition is completed. The goal is a continuum of care in the transition process,” Doulton wrote.

“As a team, we are reinforcing to our patients and families that SCD is only part of them, not their entire identity. Regularly in our center we stress the positive aspects about life's struggles, acknowledging that is it hard and it is sometimes not fair. During the development of this preparation program, one area that required tactfulness was the area of career/vocation as it involved talking about the hopes and dreams of the patient. It is truly a delicate situation to assist the patient to strive for their dreams with consideration of the realities of having a debilitating chronic illness that is unpredictable,” Doulton wrote.

“Our main goal is that children being cared for in our sickle cell center will be knowledgeable about their disease and actively participate in all aspects of their health care from cradle to commencement. It is our hope that through our collective efforts of our team that these patients will be much better prepared for a long successful future, living well with sickle cell disease,” Doulton concluded.

**Editor's Note:** Please see the article for additional information, including author contributions and affiliations, financial disclosures, funding and support, etc.

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