

Team Eases Transition to Adult Spina Bifida Care

BY DAMIAN McNAMARA
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DENVER — Lessons learned by clinicians at a multidisciplinary program regarding the transition of pediatric patients with spina bifida to an adult medical home can help others meeting the same challenges, according to a presentation at a meeting on pediatric neurologic surgery.

"As patients with spina bifida reach adulthood, there is an ongoing challenge," Dr. Hector E. James said. "Most of us know the difficulty of finding an adult medical home for patients we've seen for years in a multidisciplinary setting. There is a lack of knowledge amongst adult health care providers as to the needs of the young adult with spina bifida."

Some answers may come from the Jacksonville Health and Adult Transitional Services (JaxHATS) program. Dr. James reported that JaxHATS has successfully transitioned patients from the spinal defects clinic at Wolfson Children's Hospital in Jacksonville, Fla., to an adult medical home.

The program, launched in 2005, includes a pediatrician, internist, nurse-coordinator, unit manager, and medical social worker.

It can be a challenge to find neurosurgeons who are willing to become primary care providers for young adults with spina bifida.

"I am obviously generalizing, but it's not an uncommon problem," he added at the meeting, which was jointly sponsored by

the American Association of Neurological Surgeons and the Congress of Neurological Surgeons.

A meeting attendee asked how the JaxHATS clinicians get "buy-in" from adult providers. "We were fortunate in finding a pediatrician and internist who were willing to do this," Dr. James replied.

These doctors assess the teenager and then educate the adult subspecialist about their special needs. Also, "incorporating an educational component for residents at our academic institution helped gain acceptance from administrators," said Dr. James, a pediatric neurosurgeon at the Lucy Gooding Pediatric Neurosurgery Center at Wolfson Children's Hospital.

The adolescent and family are prepared for the transition process into adulthood

during visits to the spinal defects clinic. Then intake information is taken by the JaxHATS staff.

The clinic coordinator and nurse-coordinator prepare a "transition medical summary" for the pediatrician and internist. Insurance reimbursement must be established in advance, Dr. James said. "It is extremely important to have insurance paperwork done correctly for the first appointment. The social worker and manager assist families with this and follow-up appointments."

An initial 16 patients have successfully completed the transition. Although the JaxHATS program "is still a work in progress," Dr. James said, "it is a very rewarding experience. It may not be a model for everyone, but it worked for us." ■

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