

Daniel's Story

Three years later, he's eating and breathing on his own-and he's been to Disney World

By Karen Hardwick, PhD, OTR, Len Feichtinger and Debbie Wiederhold

Photos by Diana Welsch

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aniel Wiederhold was first introduced to the readers of *TeamRehab Report* in November 1994, when he was 2 years old and living at home for the first time. Daniel has diagnoses of osteogenesis imperfecta, Type II; respiratory insufficiency; feeding problems and hydrocephalus. He also has a tracheostomy.

Daniel spent the first 14 months of his life in the neonatal intensive care unit of SetonHospital in Austin, Texas. Early in his life, his parents, Debbie and Don Wiederhold, his brother Tommy, and his sisters Jennifer and Erin were told that Daniel would probably not live past 2 months. Daniel exceeded everyone's expectations and, after he was discharged from the neonatal ICU, he moved home with his family and a staff of nurses who provide 24-hour care.

Daniel is now 5 years old, and he no longer depends on a ventilator for respiration. He has not used his ventilator or oxygen since Christmas 1996. He formerly received most of his nourishment by gastrostomy tube; he now eats and drinks orally and feeds himself finger foods. His favorite snacks are pretzel chips and Chee-tos.

Daniel formerly received therapy, educational and nursing services almost exclusively at home. He still requires 24-hour nursing services because of his serious medical condition. He receives most of his skilled nursing from his private insurance company, Prudential Plus, and, to a



Daniel's original mobility system in 1994 had to accommodate a ventilator system and keep him upright. With that system, Daniel began to exhibit head movement and functional use of his arms, and bear some weight on his legs.



Daniel, pictured with his mother, uses a switch at his hand to activate a Cheap Talk Combo Direct Scan for simple messages.

lesser degree, from the Medically Dependent Children's Waiver Program. That is a federal program administered by the Texas State Department of Human Services.

Daniel now attends Deepwood Elementary public school three times a week for four hours a day. He rides to school in his new wheelchair in an accessible minivan from a local cab company. He continues to receive occupational, physical and speech therapy, and at-home instruction from the

Round Rock Independent School District. He uses a computer at school to improve communication and cognitive functions. He also uses a foot-operated pressure switch that emits a beep for signaling, and he uses a Spec switch with his hand to activate a Cheap Talk Combo Direct Scan for simple messages such as "I would like a cracker, please" and "Please read me a story."

When Daniel first moved home from the hospital, the Wiederholds used a double-long twin stroller to transport Daniel and his oxygen bottles, life support machinery and other supplies around the house and to outside activities. In the stroller, Daniel was limited to a flat, supine position because his neck could not support his head. This position mimised his respiratory function; limited his arm use because of his inability to lift his arms against gravity; restricted his visual field; and reduced his opporhmities to interact with the environment. The family found maneuvering the long wheel-based stroller very difficult, and the height of the stroller made transferring Daniel laborious and dangerous.

staff fabricated a seating system that supported Daniel safely, out of his customary supine position, while providing a more user-friendly mobility device. The staff consisted of Hardwick, the team leader; Len Feichtinger, chief wheelchair technician; Sara Stewart, COTA; Donna Millenbach, COTA; Jim Tuttle and Robert McGraw, wheelchair technicians; Maxine Johnson, Daniel's nurse; and his parents.

A foam-in-place insert of Sun-Mate foam was constructed to provide total contact and evenly distribute support and protection for his neck and limbs. The insert was placed in a custom-made ABS plastic bucket and mounted on an Everest & Jennings Traveler manual wheelchair with a standard wheelbase using four horse-

shoe clamps so the integrity of the frame was not disturbed. Friction locks (Mechlok, MM85-1012, by P.L. Porter) were used to provide tilt in both frontal and sagittal planes.

The seating device met the family's concerns about Daniel's medical condition by providing support for his hydrocephalic head and

allowing precise placement to avoid compromising his tracheostomy. Daniel's system enabled him to attain a semi-upright position through modification of supine lying. He was not able, however, to sit in a conventional seating system. The first seating system allowed Daniel to maintain a more upright position against gravity, and he eventually began to exhibit head movement and functional use of his arms. He began to bear some weight on his legs, which began to straighten out of the totally bowed position.

Daniel's seating system underwent a number of revisions as Daniel grew and as his sitting ability and upper extremity function improved. In July 1996, he took his first

As Daniel spent more time upright, his trunk and upper-extremity control continued to improve.



Daniel now uses a Kid-Kart EZ frame with a special foam-in-place seating system.

A switch at Daniel's foot emits a beep for signaling.

airplane trip. He traveled on the plane in his seating insert, which was removed from the mobility base and placed in a regular plane seat. He spent a week in Florida, having a wonderful experience at Disney World through the generosity of the Foundation for Hospice and Home Care. He concluded his experience by attending the national conference of the Osteogenesis Imperfecta Foundation.

As Daniel spent more time upright, his trunk and upper-extremity control continued to improve. In August 1996, his orthopedist agreed to prescribe a mobility base that would allow Daniel to sit in a more conventional position. A Kid-Kart EZ was purchased through Prudential Plus. The Kid-Kart was furnished with a ventilator tray, battery tray, large wheel option, sun shade, floor sitter base, and high chair base to allow Daniel to sit at the table with his

family for meals. The frame is safety approved when used as directed with the bus tie-down system.

A new foam-in-place insert was constructed to provide even support and pressure relief and to protect his neck and limbs. Daniel was positioned on 2 inches of Sun-Mate foam placed in the wheelchair. His head and limbs were supported in the desired position, and he could still reach his foot and hand switches. Foam-in-place was poured into a bag placed underneath him. The resultant form was trimmed and refined,

and the completed insert was covered in a combination of materials.

The back was covered with cloth-side Rubatex to add color and relieve heat on his skin. The seat was upholstered in smooth-side Rubatex for moisture resistance. The headrest was covered with Darlex to provide a silky surface to prevent matting of his hair. The straps, frame, seat pans and other structural features of the Kid-Kart were not altered so it would retain the safety rating.

Although Daniel's family has a van equipped with a tie-



A new foam-in-place insert was constructed to provide even support and pressure relief and to protect his neck and limbs.

down system, they would like to have a safety-approved child restraint system in a standard automobile and for use on plane trips. Because of his improved sitting ability, Daniel may soon be able to be placed in a commercially approved car seat. Another plane trip may be imminent if Daniel takes part in a study at the Shriners' Hospital for Children in Montreal, Canada. The study is designed to evaluate the effect of Pamidronate, a bone reabsorption blocking agent widely used in adult forms of osteoporosis. The anticipated outcome of the study is to increase bone mass, reduce number of fractures, reduce bone pain, and increase mobility. As Daniel's health and functional skills continue to improve, additional rehab technology may be able to assist him in reaching his maximum potential.

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