

# Meet Robin...



## **ROBIN HAS ATHETOID CEREBRAL PALSY.**

People with this disability have trouble holding themselves in an upright, steady position for sitting or walking, and they often have involuntary motions. Athetoid cerebral palsy is a lifelong disease with symptoms that become more significant as the person ages. Despite her physical disability, Robin is a bright, intelligent young woman.

It takes a lot of work and concentration for Robin to move her hand into certain positions. For example, scratching her nose, reaching for a cup or manipulating the joystick on her power wheelchair are all challenging tasks. Because of her uncontrolled movements and trouble maintaining a position, Robin is often unable to hold onto and manipulate objects in her environment. Though she cannot speak, she is able to communicate using an electronic speech-generating device. Robin cannot walk, so she uses a power wheelchair for mobility.

Robin's power wheelchair saga began when well-meaning support staff contacted a wheelchair sales company that advertises on late-night TV and the Internet. This company has little or no experience in providing equipment for people like Robin who have severe postural deficits and mobility disorders.



The power wheelchair supplied was a disaster for Robin, her family and the funding system that paid the inexperienced wheelchair company for the inappropriate equipment.



Fortunately for Robin, there are skilled, knowledgeable and compassionate individuals in her part of the country who were willing to help. Karlyn, her therapist, and Michele, her CRTS®<sup>1</sup>, corrected the situation caused by the original wheelchair sales company.



They started the process by reviewing Robin's functional and physical needs, and by performing an extensive evaluation of posture, movement and function as it related to her environment, mobility and quality of life.

<sup>1</sup>CRTS® (Certified Rehabilitation Technology Supplier®) is registered with the National Registry of Rehabilitation Technology Suppliers (NRRTS) and certified by RESNA, the Rehabilitation Engineering and Assistive Technology Society of North America.



State-of-the-art equipment was used to simulate and test various positions to maximize Robin's comfort and function. The simulation process took hours, requiring multiple sessions over a few days to achieve optimal results. Various factors were carefully weighed before final equipment specifications were developed for both the postural support system and the power wheelchair.



## *Success!*

Robin has gone from sitting in an ill-fitting, nonfunctional power wheelchair supplied by an inexperienced, unqualified wheelchair sales company to being able to use her speech-generating device, turn her head from side to side in a controlled manner, use her arms and hands for functional activities, drive her power wheelchair and interact with people in her environment.



With the help of qualified individuals, and through the application of sound postural seating and wheeled mobility concepts, evaluation techniques and technology, Robin finally received the seating and wheeled mobility system she required.

## *What you can do to help people like Robin!*

Basic home medical equipment (HME), such as the original power wheelchair supplied to Robin, and complex rehab equipment, such as the chair evaluated and specified by Karlyn and Michele, are as different as night and day. The skill level, experience and knowledge base required for providing appropriate complex rehab products and services does not exist in the basic HME world.

To assure individuals like Robin get what they require and that these products and services are supplied in an appropriate and cost-effective manner, complex rehab products and services must be assigned a separate benefit category under the Medicare program. The complex rehab category must include its own supplier standards and qualifications, coverage policies, HCPCS

code set and fee schedule.

All legislative and regulatory decisions made on Capitol Hill and by CMS impact every person with disabilities who require these services, regardless of age or diagnoses. Medicaid and private insurers all eventually follow Medicare's lead, so the decisions that seemly affect only older Americans with disabilities have a profound influence on infants, children, teenagers and adults, regardless of their disability or health-care coverage.

If you agree that Americans with significant, complex postural and mobility impairments should have the equipment they need, then **we urge you to support a new benefit category under the Medicare program for complex rehab equipment and services.**



For additional information, please contact Simon Margolis, executive director of the National Registry of Rehabilitation Technology Suppliers, today at 800-976-7787, or visit [www.nrrts.org](http://www.nrrts.org).