

# Norman's Conquest

## An ECU Opens Up the Possibilities

By Susan Drastal, MS, and Cindy Nead, COTA

Norman, a healthy, 51-year old male, experienced a sudden onset of a viral illness that led to weakness throughout his body. While hospitalized, his condition deteriorated to the extent that he was placed on a ventilator and tube-fed, all within one week. Norman was diagnosed with the axonal form of Guillian-Barre syndrome.

An acute, rare autoimmune disease of the nervous system, GBS involves the spinal nerve roots, peripheral nerves and occasionally cranial nerves, often following a mild undiagnosed respiratory or gastrointestinal illness.

Usually, only the myelin (the covering of the nerves) is affected and patients have a good prognosis for recovery. However, in a small percentage of cases, the axon may also be affected. The axon is the process of the nerve cell along which impulses travel away from the cell body. Patients diagnosed with motor and sensory axonal GBS often experience slow recovery and severe residual disability.

The acute stage of GBS has a rapid onset of paralysis, which may affect all four extremities at once or start in the legs and spread upward to the arms. This may also be accompanied by sensory loss and muscle atrophy if there is axonal injury. Nerves regenerate at the rate of about 1 inch per month. With axonal GBS, the damage is near the cell body where recovery starts proximal with distal atrophy. However, in most cases of GBS, there is no need for nerve regeneration, only remyelination.

In June 1996, following two months in an acute care hospital and many medical complications, Norman was admitted to Kessler Institute for Rehabilitation in West Orange, N.J. He was ventilator-dependent, had trouble swallowing, needed to be tube-fed, and functioned as a person with C2 quadriplegia. He was able to move his head and neck and also had slight shoulder

shrug. Other voluntary movements included left ankle plantar flexion, extension of his toes on his right foot, and minimal movements of the distal joints of his fourth and fifth fingers of the right hand.

Within one day at Kessler, Norman progressed to nocturnal ventilation. He was weaned off the ventilator within one month, and then had his tracheostomy capped until it was removed the following month without any problems.

Besides himself, Norman's rehab team included his medical doctor, occupational therapist, physical therapist, speech pathologist, rehabilitation technologist, respiratory therapist nurse, and case manager.

His OT's goal was for Norman to achieve the maximum amount of functional independence and exercise to include mobility, self-care, leisure activities and vocational skills, in addition to evaluation of all necessary and appropriate equipment. His speech therapist, who treated him for about one month, wanted Norman to achieve functional voice volume for conversations and swallowing to eat regular textured foods. Respiratory therapy goals included achievement of pulmonary sufficiency with removal of his trach. Physical therapy goals included increased muscle strength, vital breathing capacity, and tolerance to sitting upright. Social services' goal was to secure a discharge plan and home placement with the long-term goal of returning to work in some capacity.

Due to Norman's severe limitation of movement and decreased strength, the range of switches from which to choose was narrow. He called the nurse by using a pancake single-switch, placed on his pillow, which he activated with his head.

Norman's first experiences with technology also involved controlling his wheelchair. When he was able to tolerate sitting up, he began experimenting with power wheelchairs.

Norman was offered two switches to try: sip-and-puff and the proportional head array. He tried the pneumatic sip-and-puff switch and within a day became proficient in maneuvering his wheelchair through Kessler's hallways and in tight spaces.

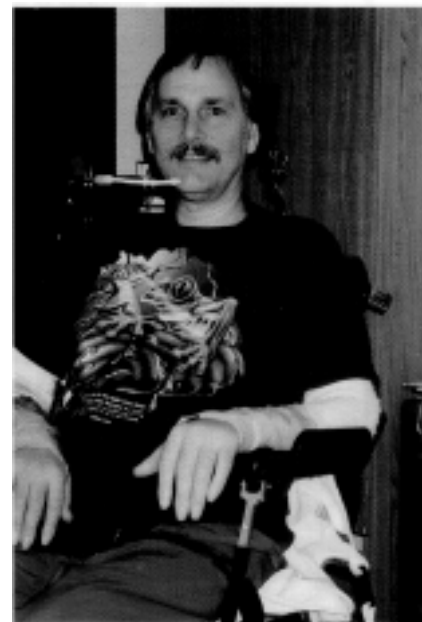
Two weeks later, the head array was introduced. Norman didn't like this method due to extraneous movements of his head and neck (i.e., having to continually move his head in several directions). He believed it wasn't safe for him to drive and carry on a conversation simultaneously. He also complained of neck stiffness after driving for long periods. Norman also did not care for his appearance while using the head array.

Chin control was another option, but, in addition to the problems with head movement encountered with the head array, Norman did not like having the chin control directly in front of his face.

He was eventually prescribed a Quickie power wheelchair with a LaBac tilt and sip-and-puff control.

Norman, a highly intelligent man, had been director of the vascular lab at a large medical center. Because he was familiar with technology and computers, he knew that controlling devices in his environment was not only possible, but something he would like to pursue. He wanted to become independent in his environment and return to work.

Norman was very involved with his medical and therapy care, and enjoyed



Despite having a tracheostomy, Norman preferred the control and accuracy of the sip-and-puff switch.

problem-solving technology issues. He possesses a unique ability to create innovative ways to approach new problems.

For example, he wanted to keep up with current events and listen to classical music on the radio. It became apparent that Norman needed an environmental control unit. However, Norman's radio was not programmable, so the ECU could only turn the radio on and off, not change the volume or station. Norman suggested using two radios—one pre-set to a news station and another to a classical music station. These two radios were plugged directly into an X-10 module that was controlled by the ECU, which Norman activated via a pneumatic sip-and-puff switch.

After a couple of days, Norman became interested in controlling the telephone, his bed and his television. Having private telephone conversations was important to him. The ECU allowed some privacy, but required that a headset be placed on the user's head. Norman didn't

Norman decided he was interested in the following features: a wireless remote to control his ECU from his wheelchair, a voice-recognition system to control his computer; a system that could be controlled with either his voice or a switch (for times when his voice was not strong enough to be recognized by the unit); telephone conversation privacy; and a manufacturer with local dealers and representatives to help with installation, training and trouble-shooting.

Norman chose the Simplicity All-in-One Plus by Quartet Technology, which includes a Voice Mouse/Keyboard (VMK) for controlling his computer. He liked that the Simplicity could be controlled with a wireless remote from his wheelchair. None of the other ECUs to which he was exposed had all of these features.

The Simplicity Series All-in-One is a voice- and switch-activated ECU with voice output. The audio output allows the user to receive feedback to confirm his actions. Environmental control is determined through a series of verbal commands or by using any ability switch. The All-in-One also adds a special audio interface allowing direct connection to many popular speech-to-text computer products.

The Voice Mouse/Keyboard, a unique feature of the Simplicity, is a state-of-the-art system designed to provide a complete voice interface, allowing full control of both the keyboard and mouse functions for any IBM-compatible personal computer. It is

operating-system independent, which means it works, for example, with Microsoft Windows, Unix, OS/2 or DOS. The VMK, which does not require any special software or hardware, also allows the user to access the computer remotely (wirelessly), to reboot the computer, and to control appliances while working on the computer.

The All-in-One also allows Norman to control the telephone hands-free. He can answer, dial, speed-dial, hang up, have a private phone conversation (through a pillow speaker), handle call-waiting, and adjust the volume of the telephone.

Norman worked closely with James Stickle, owner of Integrated Technologies and a certified Simplicity representative/dealer, to set up the system and train him. Stickle worked with Norman while he was still an inpatient at Kessler and at Norman's extended care facility

on Staten Island, N.Y. (he was discharged from Kessler in September 1996). The entire equipment package was ordered in mid-September, and delivery and training started the first week in October.

Once Norman knew what kind of computer he needed, it was purchased in December, and the final installation and training occurred in January 1997. The total cost of the equipment from Integrated Technologies was \$11,090.

## Norman's equipment list:

1 Simplicity All-in-One Plus ECU (includes Voice Mouse/Keyboard with cables for computer) with bed microphone

■ Bed cable for Hill-Rom#822 Bed

■ Sip-and-puff switch with 30-inch throat in mouthpiece and bed bracket

■ Pillow speaker for telephone

■ Three appliance modules for radio, CD player and computer

■ Three lamp modules for lights

■ Radio remote for power wheelchair with charger

■ Extra battery for radio remote

■ Microphone package for power wheelchair

■ Training and installation (10 hours)

■ Call-button cable and wall jack

Funding for the ECU was provided through an anonymous donation to the Young Israel Community. Norman's medical insurance from his job paid for his Quickie power wheelchair, but would not pay for the durable medical equipment because he was discharged to an extended care facility.

Norman's social worker at that facility is pursuing funding for transportation to work and any work-related activities through vocational rehabilitation. Norman has consulted with a transportation company that allows people to rent a wheelchair-accessible van. He used this service to visit his work site and discuss future employment, possibly by telecommuting. ■

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Norman presently is using the ECU package daily, which he accesses via a bed-mounted microphone or, while in his wheelchair, a remote microphone. Norman says his goal is "to be as independent as I can."

want to ask someone to place this headset on his head each time he made a phone call.

A Teledyne/Brown Imperium 200H ECU was set up, and he used this ECU within his semi-private hospital room for several weeks with proficiency.

Another important activity for Norman was reading business journals. A page turner—the Touch Turner—was set up on an over-bed table, which he was able to access independently. For this device, Norman felt comfortable using a chin control to turn the pages, needing someone only to set the magazine on the bookstand.

Several weeks before discharge, his OT wanted to give Norman more options for ECUs. She arranged for several vendors to meet with him at Kessler, so he could make an informed decision. After seeing several models and types,