Ventilator-Assisted Living
June 2010 Vol. 24, No. 3
www.ventusers.org

Twin Vent Users

Nancy Nolan, twin2nan@gmail.com; Sheila Nolan, twin1she@yahoo.com;
Boston area, Massachusetts

My sister Sheila and I are identical twins who have been challenged with limb girdle muscular dystrophy (LGMD) since the age of eight. Being diagnosed with muscular dystrophy was no easy task for the doctors.

Sheila (left) and Nancy

At age two, I was hospitalized in isolation for two weeks with polio, which only left me with a limp. At age eight, Sheila started limping exactly like me. Because we were such closely-knit twins, people thought that the limp was out of sympathy for each other. Our mother became quite concerned and took us to our pediatrician who told her she was just a young mother worrying about nothing.

After observing us climbing aboard the school bus differently than the other children, she decided to take us to Children's Hospital in Boston. It was there that a muscle biopsy confirmed a diagnosis of muscular dystrophy. The prognosis was terrible: we would not walk after our teens nor live out our 20s. But we proved them wrong, walking until we were 25 and living well beyond our 20s. We are now 63.

When we turned 34, Sheila started having trouble breathing but because she had a very stressful job, our mother and I kept telling her it was nerves. We almost killed her. She suddenly lost a lot of weight, and her voice became very soft. Thus began our love affair with Nicholas Hill, MD, our pulmonary doctor. When Sheila went to see Dr. Hill for the first time, a blood gas test confirmed she was indeed having trouble breathing. After a few visits, Dr Hill told her she needed to start using a ventilator.

My whole family was shocked because we associated a ventilator with death, not life. Oh, how wrong we were! We have lived full and productive, happy lives for 30 years, despite needing to use our ventilators all the time. Now we use a bilevel unit with nasal pillows during the day and a nasal mask at night. When we go out, we use a mouthpiece with the HT50® ventilator that hangs on the back of our power wheelchairs.

We have traveled extensively, mostly when we only needed to use the bilevel at night. Dr. Hill likes to tell the story of Sheila using the pneumowrap, a breathing machine that was like a vacuum cleaner. It took two personal care attendants to get her comfortable in it. I started using the bilevel, then new on the market, and decided to take a trip to Disneyworld,

continued, page 5

Another insurance issue was trying to get my insurance company to state in writing that my level of nursing coverage would not be decreased when I become a DPS user. Currently I receive 44 hours per week of nursing coverage and my family covers the remaining 124 hours. For them to cover more would be quite difficult.

I wrote to my insurance company to explain that even as a full-time DPS user, I would still be dependent on a mechanical device to help me breathe, and the rest of my care would essentially remain unchanged. However, the insurance company replied that a "clinical review" would be necessary to determine the level of care I need after I get the DPS.

I wasn't pleased with that reply until I spoke with a Florida friend who has the same insurance company and has been a DPS user for over five years. He told me that he receives 16 hours per day, 7 days per week, of nursing coverage, for a total of 112 hours. He also knows another DPS user with the same level of care and same insurance. Now I'm not concerned about a clinical review and might even be able to increase my nursing coverage. (For anyone who might have the same concern, Dr. Onders said that no DPS user has had his/her level of insurance coverage decreased, and it shouldn't be an issue for anyone.)

I don't have a firm surgery date yet, but I am hopeful it will be late June or early July. Stay tuned for Part III about the surgery. ▲

For more information about the DPS System, go to www.synapsebiomedical.com

Twin Vent Users

continued from page 1

leaving Sheila home. I had been trying to convince her to try the bilevel but she always found change difficult. After I went to Florida without her, she finally tried and succeeded with the bilevel. Since then we have both gone to Disneyworld together.

You would think living with a ventilator would be difficult, but it just becomes a way of life. You can choose to think of it as a burden or you can just enjoy each day as it comes. We are not saying that living on life support systems has not been challenging, but we have wonderful caregivers who like to have as much fun as we do.

Our summers are our time for fun! Last summer we traveled to Maine, Rhode Island, and many places in the Boston area in our van. When traveling in the van, we wear our neck braces and chest straps. Our necks are very weak and floppy, so finding these neck braces (See Headmaster Cervical Collar™ details on p. 6.) was a great blessing and changed our lives.

We had a sine-wave inverter installed in our van so we could use our CoughAssist® when traveling as well as plugging in the bilevels anytime.

When we arrive at our destination, we turn on the HT50® ventilators on the backs of our wheelchairs and use them as we sightsee. People have told us we are like the Energizer bunny; we just keep on going! ▲