

# My Search for the Solution

Jean B. Davis, Albany, Georgia

*After five days as an inpatient at Vanderbilt Stallworth Rehabilitation Hospital in Nashville, Tennessee, under the care of Brenda Jo Butka, MD, and her staff of respiratory therapists, I am able for the first time in months to breathe adequately at night, to sleep, and to function at optimum capacity during the day.*

I contracted polio in 1953. It left me quadriplegic and dependent on the iron lung for five months. I left Vanderbilt University Hospital two months after being weaned from the iron lung and was able to breathe without any respiratory assistance. My almost total quadriplegia continued, however, and that condition worsened over the years as I experienced the late effects of polio.

The late effects of polio also caused my breathing capacity to deteriorate over the years, and about 12 years after I left Vanderbilt, I began to need help with my breathing during the night. I started using negative pressure ventilation with a cuirass and the Monaghan 170C ventilator. Then, with the passage of 15 more years, I began to require assistance during the daytime, using an early PVV ventilator with mouthpiece and then a PLV®-100 volume ventilator with mouthpiece during my waking hours. I continued to rely upon the Monaghan and cuirass during the night.

About two years ago, I began to have problems sleeping. I did not seem to be getting enough breath to allow me to relax and go to sleep. My equipment provider substituted a NEV®-100

for the Monaghan to drive my cuirass, and my breathing problems at night noticeably worsened. Because the exacerbation of my breathing problems coincided with the use of the NEV®-100, I erroneously attributed them to the equipment.

I was unable to find anyone in this area – southwest Georgia – who could offer any solution to my breathing problems, (although a therapist suggested that I might need to use the iron lung again), until one day in 1998 when I was discussing the problem with the manager (a registered respiratory therapist) of my equipment provider in Atlanta. She gave me the name of Brenda Jo Butka, MD, Medical Director of Pulmonary Services at Vanderbilt Stallworth Rehabilitation Hospital since 1995. I contacted Dr. Butka and was in the process of arranging an appointment when my van was rear-ended by a truck, and I sustained a broken left hip. That interrupted my plan to travel to Nashville to see her.

My breathing problems at night continued to worsen, however, and I began trying to supplement the NEV®-100 and cuirass with the use of my old PVV positive pressure ventilator and mouthpiece. This did not work, and early in 2000, I again contacted Dr. Butka and arranged to enter Vanderbilt for evaluation and treatment.

Although I dreaded the trip – nine hours by automobile from my home – it was apparent from the first that Dr. Butka and her staff were eminently experienced and competent in the kind of



breathing problems I was having. That in itself was encouraging and reassuring.

When I went to Nashville, I was apprehensive that the solution to my problem would be to return to the iron lung. This would have meant a substantial diminishment in my quality of life, and I dreaded the prospect. Dr. Butka put those fears to rest immediately. She made it clear that the solution to my problem was yet to be determined, but the solution was not the use of the iron lung or negative pressure ventilation in any form.

During the ensuing five days of my stay at Stallworth, Dr. Butka confirmed that using negative pressure ventilation equipment during the night was inadequate for me. My oxygen saturation levels were substantially below normal, which accounted for my feelings of breathlessness, inability to sleep, and the general feeling of malaise during the day.

It was decided that the use of a positive pressure volume ventilator (I use the PLV®-100) with nasal mask at night was the appropriate solution. I had been told about this option at home, but I was not convinced that this

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was the proper solution to my problems. There appeared to be no one at home who could guide me in the use of these options, and I had not really given the masks a fair trial. They felt uncomfortable and intolerable, and I did not know how to use them correctly.

At Stallworth, I was shown a variety of masks, how to properly use them, and how to deal with the problems of skin irritation and discomfort. I also became convinced that use of the mask would solve my breathing difficulties.

The first night with the nasal mask I slept six hours and my oxygen saturation levels went up to 98% and 99%. The next night I slept eight hours, and thereafter I had eight and nine hours of uninterrupted sleep.

My oxygen saturation levels continued in the range of 98% and 99%. Since I have returned home, I am sleeping as I have not slept for months and my oxygen levels remain at the 98% level.

I now use Mallinckrodt's Breeze™ SleepGear™ (which contains ADAM nasal pillows with tubing going up over the nose and forehead, held in place at the back of the head) and find it the most comfortable for me. ■

Brenda Jo Butka, MD (615-963-4032)



**IVUN News**, the quarterly newsletter of International Ventilator Users Network, is dedicated to providing up-to-date news about living at home with a ventilator. Edited by Judith R. Fischer, the 8-page newsletter features articles written by health professionals and ventilator users who describe their experiences to educate others. It also includes a calendar of related meetings, notices of articles and new books, and new equipment and interfaces.

The subscription rate is \$17 in the USA; \$22 for overseas surface, Canada, and Mexico; and \$27 for overseas air. A set of back issues (from 1993-2000) is also available for \$20 in the USA; \$25 for overseas surface, Canada, and Mexico; and \$30 for overseas air.

**IVUN Resource Directory**, revised annually in the fall, has been described as a "gold mine" with contact information for health professionals, ventilator users, equipment and mask manufacturers, service and repair, and related organizations.

Numerous *IVUN News* articles and the *IVUN Resource Directory* can be found at [www.post-polio.org/ivun.html](http://www.post-polio.org/ivun.html).

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