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Arriving at Correct Diagnosis, Treatment:

A Long and Frustrating Process

More than a year ago, after strenuous exertion, I became very short of breath and dizzy, and realized that I had gone into atrial fibrillation (A-Fib). In the emergency room, the cardiologist focused on my being 61 as the cause. I had a normal lipid panel and a normal stress test. I reviewed A-Fib causes online and found that sleep apnea was a possible underlying cause and that post-polio syndrome (PPS) was associated with sleep hypoventilation. (I contracted polio at age 4 in 1953.) I asked the cardiologist for a pulmonary consult. He flatly refused, telling me to accept that I was just getting older.

This first-person account was written by a retired physician who, for personal reasons, prefers to remain anonymous. The author spent a year in a rehabilitation hospital after contracting polio at age 4 and went on to become an accomplished skier until the late effects of polio curtailed active participation in outdoor sports.

This account highlights the struggle some people with neuromuscular conditions face in finding appropriate consultation and treatment, particularly if they do not live near a major medical center.

Over the next five months of multiple meds, the A-Fib became more frequent and was always very symptomatic. I was dizzy and short of breath even walking 20 feet. Episodes would last for an hour or two. At every cardiologist and electrophysiologist visit, I explained the polio/sleep hypoventilation concerns and requested a pulmonary consult. They both refused repeatedly.

After four months of paroxysmal A-Fib, I had to quit my job. I obtained my records and test results and noticed that my ultrasound indicated severe pulmonary hypertension and blood count showed high hematocrit of 46. I have never smoked, rarely drank, never used drugs, did not have COPD, lived at only 800 feet altitude and had become sedentary because of the A-Fib. So there was no reason for such a high hematocrit. High hematocrits correlate with hypoxia (oxygen deprivation), again suggesting sleep hypoxia.

Seeing the worrisome ultrasounds indicating severe pulmonary hypertension, I contacted the local medical school pulmonary hypertension clinic nurse. She took my polio and pulmonary concerns to her pulmonologist. He understood and set up pulmonary function testing.

A full six months after the start of A-Fib, the medical college pulmonologist discovered that while sleeping I had 97 minutes below 88 percent oxygen saturation, with hypoventilation, obstructive sleep apnea. The official diagnosis is now chronic respiratory failure, neuromuscular type. He sent me to a neurologist who did EMG/NCV (tests that record the electrical activity of muscles and nerves) and confirmed the extent of my prior polio.

I have new weakness in muscles not previously affected as well as new breathing and probably swallowing concerns. She said the left leg collapsing despite reasonable muscle bulk was because I had a reduced number of motor neurons going to my muscles. When I used my muscles a lot, their neurotransmitters became depleted more rapidly and would stop working.

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A Long and Frustrating Process

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She told me to take time to sit down and rest during the day to replenish my neurotransmitters. She is right. Even a five- or 10-minute rest at a store or mall gives me much added strength.

The pulmonologist sent me to an electrophysiologist who did an excellent cardiac ablation (a procedure that cauterizes an area of heart muscle) that has kept me A-Fib free so far. Post-ablation, I started on food supplements and a fitness program which doubled my strength in three months. I can now do ordinary tasks easily again, like getting up from chairs, going up stairs and closing the hatch on my SUV.

After six months I went off warfarin (an anti-coagulant), and after seven months, I went off dronedarone (cardiac arrhythmia medication).

A cardiac catheterization done at the same time as the ablation showed that the pulmonary hypertension was either nonexistent or mild. The high-risk anesthesia team pulled me smoothly through that eight-hour procedure. Post-op, my X-ray showed obvious atelectasis (lung collapse), and I said it's time to start CPAP. So I stayed on the hospital CPAP 24/7 until discharge.

The evening of discharge, they brought CPAP to my home. It was a ResMed AutoSet with an H5i heated humidifier, and a ResMed Mirage Quattro full face mask, size medium. As I became used to this CPAP, I noticed that one to three times every night I would awaken from a deep sleep with the CPAP putting out its top pressure of 20, and the mask slapping my face hard with pressure leaks into my eyes.

I kept tightening the mask but developed a worrisome pressure sore on my nose. I bought a ResMed Gecko gel nasal pad, size medium, which helped considerably. But I developed unilateral diplopia (seeing double) in both eyes and wondered if it was from excessive mask pressure and the large gel pad. No one knew. I bought a smaller mask, and I also bought a second Gecko nose pad, size small. The diplopia became milder but is still present.

Even with the smaller mask strapped on tightly, on CPAP every night I would be awakened by the pressure at 20 burping out of the mask which kept slapping my face. With the mask super tight, I would awaken at the top of a breath, and it felt like I was trying to breathe out into an already full balloon pushing back at me.

Neither the pulmonary nurse nor the CPAP nurse understood the problem. So it was back to online searching. Several websites suggested that people with PPS needed BiPAP. I contacted IVUN describing my mask pressure problem, and the information IVUN provided seemed to indicate that I needed BiPAP.

The pulmonary hypertension pulmonologist understood immediately. He referred me to the sleep specialist pulmonologist who handles neuromuscular ventilation needs. She did some more testing that qualified me for BiPAP. My insurance gave me a Philips Respironics BiPAP AVAPS. She set this on variable IPAP 4 to 25, EPAP 4, backup breathing at 8, tidal volume at 450 ml. I tried different rise times and decided the 1 setting felt best.

After almost a year, I use the BiPAP every night and do not really notice it any more. It feels easier to breathe with it on. I still use a tightly fitting ResMed Mirage Quattro full face mask, size small, with the ResMed Gecko gel nose pad.

Recently, I developed a gray spot in my central vision and an arc of flash-

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ing lights at the outer edge. The ophthalmologist found a posterior vitreous detachment, but he did not know of any association to the mask pressure on my eyes. He did feel that the previous CPAP mask high-pressure air leaks caused dry eyes that were probably the cause of the unilateral diplopia and suggested over-the-counter artificial tears four times a day.

Now that I have become so aware of my breathing, I realize that when relaxed during the day, I do not breathe well; I go into a fog and then fall asleep. In retrospect, this has been happening for about two years. I have discovered that during the fog, I can pull myself out of this. With 10 to 15 deep breaths, I become totally alert again. Also, actively rocking in a rocker while watching TV completely stops this from happening. I would be interested to hear if anyone else in the neuromuscular respiratory failure group has had experience with this and has any suggestions. If so, please contact info@ventusers.org. ▲

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This is our 26th year of publishing a newsletter.

Past issues may be found at: International Ventilator Users Network (IVUN), www.polioplace.org/history/collection/international-ventilator-users-network-ivun

CLICK HERE TO LEARN WHY

Smartphones? iPads? Tablets? Do you use any of this technology in connection with your vent therapy? If you could somehow 'connect' all of your caregiver communications, prescription information, progress reports, sleep logs – anything connected with your vent therapy – through one of these devices, would you use it? Please take a minute to complete a short survey. The results will be shared in a subsequent distribution of this newsletter. Thanks.

Please click here to begin.

RESEARCH REMINDER

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The deadline for Phase I application is **May 4, 2012.**

The criteria are posted at Research Fund Call for Proposals for 2012. Funds may be used for a small exploratory study or to complete an ongoing project or they may be combined with other grant funding to complete a larger project.

If you have any questions, please email info@ventusers.org or call 314-534-0475.

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