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IVUN's Ninth Educational Conference Call

My Continuing Medical Education as a Post-Polio Patient/Physician

Bonnie Jo Grieve, MD, interviewed by Joan L. Headley, Executive Director, IVUN

Introduction:

Headley: As some of you know, there is a sense that there is no need to educate about post-polio conditions due to the lack of population – it is small and is getting smaller. However, if you are the one patient of a pulmonologist, his/her education *is* important. It is also a misconception that all polio people who have problems with sleep have obstructive sleep apnea (OSA), which is typically treated with CPAP. Some do.

But many have breathing muscle weakness, which makes it hard to inhale and exhale. New muscle weakness in the back muscles can cause more scoliosis and thus cramped lungs and less air entering the lungs. Both of these situations also make it more difficult to cough, which causes more lung infections that are treated, but the root cause is not acknowledged, and people have recurring infections and treatment when they need breathing assistance. In the later instance, the devices of choice are the bilevels, volume vents and iVAPS – volume assured pressure support. But, people may have other conditions, too – COPD, for example.

For years, we at IVUN have been writing about this topic to provide information to both health professionals and potential users or long-time users. We can make general statements, but ultimately each of us is different and we must seek solutions that work for ourselves. Dr. Grieve did just that, and she talked about her experience, which may help others. A person's late effects of polio or even post-polio syndrome problems are best understood when we know the acute poliomyelitis history.

Dr. Grieve: I contracted polio at age 4 in 1953. At first, I was totally paralyzed and set up in a small iron lung in Queens General Hospital in New York City. A week after admission, I broke out in chicken pox and was put in total isolation for three weeks to keep chicken pox away from the children's wards. I was generally ignored, but they put me on the floor and eventually I could shuffle around and pull myself up. After three weeks, I was taken by ambulance to the New York State Rehabilitation Hospital in West Haverstraw (www.polioplace.org/history/artifacts/haverstraw) and stayed there for several months. I was discharged

with a shoulder harness, back brace and special heavy shoes. I was brought back to Haverstraw every few months for scoliosis checks, but my mother did not want to deal with scoliosis surgery, so she threw away my back brace and never took me to any further appointments. www.polioplace.org/sites/default/files/files/BJ%20Grieve%20FINAL.pdf

Headley: In post-polio circles, physicians/researchers talk about a polio person's "personal best." That is the next benchmark in a post-polio person's history. What was yours?

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Dr. Grieve: This was during my college and medical school years, ages 16 to 24, when I was able to keep up with others for most sports, including skiing and backpacking at high altitudes out West. I became solidly competent to go down black diamond runs, but used to stop several times along the way to catch my breath. I did internship and residency, used all my energy to work 80 to 120 hours a week. I emerged from those overworked years significantly short of breath compared to my peers, with diminished strength, so never went out West to ski again. In retrospect, my strength was noticeably diminished by my mid- to late 20s, but I kept lifting small weights to counterbalance the deterioration. At 35, at the end of pregnancy, I was too weak to walk 100 feet, but kept working.

Headley: When did you begin to notice some significant problems? How did you deal with them initially?

Dr. Grieve: In my late 40s, I started getting weeks of bronchitis following every cold, and this worsened with the years. At age 52, I had pneumonia with rusty sputum, the classic sign of pneumococcal pneumonia. At age 60, I did not fit the demographic for the swine flu shot, and a few days into the flu developed pneumonia again. I became aware of awakening at night more often with shortness of breath. At age 61, while working, I had to climb multiple sets of stairs with equipment suitcases and went into atrial fibrillation. Knowing about overnight polio hypoventilation, I went into the ER saying that the atrial fib was probably the result of heart conduction damage from overnight hypoxia from polio/scoliosis hypoventilation. All evaluation supported this, but the doctors refused to get a pulmonary consult and said, “accept that you are aging.” That went on for six months.

Headley: So as a physician you did not find your colleagues up-to-date. How did you deal with that?

Dr. Grieve: I switched doctors, was diagnosed with both restrictive lung disease (from severe kyphoscoliosis) and neuromuscular respiratory failure (from polio weakness). I had an ablation for the atrial fib, and post op, I had much atelectasis, was put on CPAP, but then could not breathe out against the pressure, and no one knew why. After a month of problems, I contacted PHI/IVUN and you gave me links to BiPAP which I then requested. (The pulmonologist told me that if only I started playing the clarinet, I would be totally cured.) She put me on low-span BiPAP, but I kept awakening every night with my heart pounding for the next 12 months.

Contacting IVUN led to your connecting me to internationally recognized polio pulmonologist Dr. Norma Braun, who explained that polio and severe kyphoscoliosis hypoventilation problems required high span BiPAP. So I upped my settings to high span in July 2012 and starting that same night, have been sleeping through the night ever since. Dr. Braun gave me the name of Lisa Wolfe, MD, a pulmonologist in Chicago who is familiar with polio/scoliosis ventilation problems. I saw her in December 2012. She confirmed the high span settings, set me up with a CoughAssist machine, and a stacked-breathing setup.

Headley: Briefly tell us about your setup. What breathing device do you use now? What are your settings?

Dr. Grieve: I use a Philips Respironics BiPAP AVAPS. My settings are PC mode, IPAP 20, EPAP 5, Ti (inspiration time) 1.3 seconds, volume 750, backup rate 16. I find putting on the BiPAP is very relaxing for either reading or watching TV when tired, or going to sleep. Without it, when I am tired or lying down, it takes effort to breathe; my chest feels like it has a weight on it.

I have been concerned that my insurance provider in 2011 supplied me with a much older BiPAP model. So I purchased a new Philips Respironics BiPAP AVAPS as a backup, and I use it without a humidifier in the daytime, when I get tired of breathing, to keep my pulse ox above 95. Around the house, I keep it in a smaller plastic open box along with its tubing and a mask that fits over my TV glasses, so I can easily carry it around from room to room. Without the humidifier, it is only half the size, and it can be carried around without risk of getting water into it and ruining it.

The new ResMed Quattro Air is my favorite mask. It's softer at the edges, much less eye pressure. I use it with a double thickness nasal gel pad. Second favorite mask is the ResMed Mirage Quattro, also with a double thickness nasal gel pad. Backup mask for eye pressure pain or nasal bridge irritation is the Respironics FitLife. It is a very comfortable soft-edged total face mask, even the eyes are inside. But it is noisy. And I have discovered that to keep up my pulse ox, I have to up my volume to 850 with the FitLife mask.

Headley: Earlier you said you had pneumonia many times. Is that still the case?

Dr. Grieve: I have been remarkably healthy since upping the BiPAP AVAPS settings to high span a year ago. Two mild colds resolved quickly with no bronchitis. In January 2013, despite all of us having flu shots, my granddaughter brought home the flu from day care. It was days after receiving the CoughAssist,

so I was using it per protocol. I thought I was staying healthy, but discovered that I developed considerable sputum for several days, so I upped the number of times used. Then it all cleared without an actual illness. Since then, I have had the same experience several more times. Whenever my family brings home a new cold, I noticed that the CoughAssist brings up sputum, so I use it more, and my lungs clear without any illness developing.

Headley: Do you have any other tricks you use to stay well?

Dr. Grieve: On the IVUN educational conference call a few months ago, Dr. John Bach recommended checking pulse ox readings and keeping it above 95. He stated that a dropping pulse ox may signal the start of new problems, such as an infection, heart failure or machine problems. Realizing a low pulse ox – even prior to feeling ill – alerts vent users to use their vents and the CoughAssist.

I bought a pulse ox on my own last year, and have been using it as I go about my day, both off and on BiPAP, to get an idea of what is “normal” for me. My pulse ox without a ventilator varies from 78 to 96 and varies with how hard I'm breathing, what I am doing, whether I am standing, sitting or lying down and how tired I am. It bottoms out sitting and lying down, so that is when I put on the BiPAP AVAPS. When I use BiPAP AVAPS it goes up to 96-98 no matter what I am doing. ■

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