

IVUN

International Ventilator Users Network

An affiliate of Post-Polio Health International (PHI)

“Ventilator Users Can Survive the System With Your Help”

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Judith R. Fischer, MSLS, and Joan L. Headley, MS

International Ventilator Users Network (IVUN) www.ventusers.org

Slide 1: Judith

Thank you, Dr. Sessler, and thank you to Dr. Allen Goldberg and Dr. Evi Faure, the ACCP, and the CHEST Foundation for honoring the work of our organization, the International Ventilator Users Network or IVUN. It serves people with neuromuscular conditions who use assisted ventilation longterm, such as Margaret, and this award honors them as well. Many thanks to Joan Headley, my successor, colleague, and sidekick of the last 27 years, whose vision, indefatigability, and dedication to the organization are unparalleled.

Slide 2: Joan

I, too, what to thank the College for this award. I have known many Margaret Pfrommers over the years and you will see some of them today. I have changed some of the people's names, but I have never met a vent user who did not want me to tell their story to health professionals. I share the award with several people, who are pictured here. These are the ones who take ideas and information and make it look good, as well as oversee our finances. On behalf of our organization IVUN, I want to thank Judith Fischer, who officially retired in mid-2013 after almost 4 decades of volunteer service. We would not have accomplished all of what you will see here without her.

We will weave together the history of ventilator use with the history of our organization pointing out problems and how we can all help.

Slide 3: Judith

Gini Laurie founded the organization in the 1950s. She had been a Red Cross volunteer at the Toomey Pavilion in Cleveland, one of the March of Dimes respiratory centers. When polio survivors went home from the hospital with their chest cuirasses and iron lungs and rocking beds, Gini believed they needed to stay connected to each other and provided practical information on how to live at home in their communities, to work, go to

school, travel. You can see Gini in her library, pre-Google. Gini was her own Google.

Slide 4: Judith

This was one of Gini's core tenets, and she was networking before it became a buzzword.

"Networking links people who share common needs or common goals. Networking is a support system. It is a method of self-organizing. It is the structure of a social movement. Most of all it is a method by which people get things done."

Slide 5: Judith

This is an LSD party at Gini's home to mail the early publications. LSD stood for Lick, Stuff, and Dunk in the pool. I am in the photo and had been roped into volunteering in 1967 by my aunt who was Gini's assistant editor. Gini was a master at gathering volunteers and keeping them.

Slide 6: Judith

Susan's philosophy : "I am just a normal person who happens to be lying down. That is how I feel. Even though my physical form is a little different, my life doesn't have to be."

Susan lived life to the fullest, dying just short of her 70th birthday, and having outlived all the doctors who said she would not survive. Susan was a champion frogbreather, as were many, and for many years was able to frogbreathe during the day, without using any equipment, and sleep in her iron lung at night. Anyone teach their patients how to frogbreathe? Susan lived alone, with people popping in during the day, but an attendant stayed the night.

Slide 7: Judith

You can see some of the bulky equipment in this photo of another LSD party. Polio survivors were the only vent users in the '60s and '70s, and they lived at home cared for by families. With the success of the Salk and Sabin polio vaccines, the March of Dimes stopped funding the respiratory centers that had been set up during the 1950s' epidemics. Polio survivors needed to find an alternate source of funding for attendant care, although they were primarily children and cared for by their parents at home. There was little government help at the time.

Slide 8: Judith

More examples of the older equipment – the rocking bed, chest cuirass, iron lung. Anyone still have an iron lung in their hospital basement?

Slide 9: Judith

Fast forward to the late 1970s. In response to inquiries from polio survivors about new health problems they were experiencing some three decades after the initial onset, Gini organized the first post-polio conference in Chicago in 1981, with the help of Dr. Allen Goldberg and the staff at the Rehabilitation Institute of Chicago. In the photo are Dr. Goldberg and Jack Emerson at the 1981 conference. Emerson developed the iron lung that was used most widely during the epidemics. (The latest post-polio conference was this last summer in St. Louis.) Gini published the first edition of the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors, a best-seller, in 1984.

Slide 10: Judith

These are covers of our current publications reflecting IVUN's mission. It remains what Gini envisioned: enhancing the lives and independence of users of home mechanical ventilation through education, advocacy, research and networking.

Slide 11: Judith

Gini was adamant about the need for an extra pair of hands, not making the home into a hospital.

Slide 12: Joan

I arrived at the organization on 1987 and, yes, I did hear Gini say that many times, and we still receive those emails/calls. The added problem in many states is, if someone decides to choose a nursing home, they typically are not accepted, even those who use noninvasive ventilation. There have been some creative solutions: For example, in a small town the vent user's physician was also the medical director of the facility, so he advocated with and for the vent user and arranged for her to move.

Slide 12: Joan

Another question commonly asked question was...

"How many ventilator users are there?" The number was unknown back then until this CHEST document was published in 1998. In 1990, it was estimated that there were 11,419 with 20% at home. It was also an excellent

document to assist with answering other calls. Our mission focuses on vent users living at home. However and logically, they need to get home, or back home from the hospital. Professional "Guidelines & Consensus Statements" are vital to that effort. See the list and links in the handout of the guidelines from groups around the world. IVUN would advocate for an update of this 1998 USA document.

Back to how many vent users are there. The Eurovent survey in 2005 found 21,526 HMV users in the 16 European countries surveyed. They documented vent users at home and not "all users" as the US document did.

Slide 13: Joan

A related question is: Who is a ventilator user? Margaret Pfrommer is in the upper left using mouth positive pressure; Charlotte is in the middle using a pneumobelt under her clothing powered by the PLV-100 on her chair; and also trached seen at the right. Paul in the lower left is standing at his work station. He stands all day. Paul goes to bed in the early evening with his vent and sleeps until the next morning. This is what works for him. He considers himself a vent user.

Who is a vent user? I have had RTs tell me they are vent users. Many health professionals reserve the term for those who are trached. And, that is true for many individual users, too - they are not a "vent user" until they are trached. Others who use noninvasive ventilation think of themselves as vent users, because they need assistance every night. They depend on the device to live.

As a membership organization - we offer post-polio information and/or ventilator-related information. At least 150 people a year write in bold letters on their renewal form: DO NOT SEND ME THE VENTILATOR INFORMATION. Many even send the extra money. There is a stigma and a fear connected with using a ventilator. It is something to be avoided. I am asked why we "push vents." My answer is: we don't. It is a personal choice but, for us, it *must* be an informed choice. We have published information specifically about vent use since 1987. Utilize IVUN resources.

Who is a vent user? It depends on who you ask. How many users are there? We don't know how to answer that either. A recent Market Research Report promotion states that the global ventilators market was valued at just over \$765 million in 2013 and will exceed \$1 billion by 2020 - that includes adult, pediatric, neonatal and transport vents.

Slide 14: Judith

Polio is in our organization's DNA, but in 1986, IVUN was spun off with its own newsletter, and resources. Two forces were at work. 1) The explosion of inquiries about the late effects of post-polio, thanks to the post-polio conferences, the handbook, and subsequent publicity, that was starting to consume and overwhelm staff time, and 2) the realization that more people with other diagnoses, primarily neuromuscular, such as MD, SMA, SCI, CCHS, ALS, were beginning to use a vent at home. Gini felt that the knowledge that had been accumulated by polio survivors should be shared. Later, many of the voluntary health organizations that formed around these diseases created their own materials and resources for their vent user populations. Peg, pictured here with her attendant care "family," all live with her and travel with her, but have their own wing for when they are off-duty.

Slide 15: Judith

The polio survivors who had graduated from their early respiratory devices were used to being involved in life, were married, were educated, had jobs, traveled. When they were lucky enough to learn they were underventilated, they were not interested in revisiting the old equipment and its often horrific memories. They were ready to try something new and welcomed bilevel devices for nighttime assistance, as did others with a neuromuscular disease. The long-term vent users were thrilled when the LTV appeared - light weight, much more portable and modern looking. Kathleen is shown here using her vent and grading papers in the not-so-plush faculty lounge of her university. Granted the number of people with disabilities working is low-20.1% compared to people without disabilities working: 68.5%. But do not assume your patients don't work. Listen to your patients. Advocate with your patients. Facilitate their efforts to work; children to attend school. Assist with the individualized education plans (IEP) for school-aged children.

Slide 16: Joan

Another common comment in the '90s was "Help, I need a face mask that is comfortable for me." Bud Blitzer, seated here, took the initiative in 1991 and started a Directory to assist others, which also pointed out the need. There were 10 masks included in his 1991 Directory. Seven were custom-made masks and three were mass produced by Healthdyne, Puritan-Bennett and Respirationics.

Slide 17: Joan

Thankfully for vent users, over the years, more and more options became available. The comments today are minimal. Sometimes favorite masks are

"improved" not to their liking and many wish that they could try out several before having to decide on one and purchase it. We hear from those who would like the mouth intermittent positive pressure option shown here but have trouble finding a health professional with the expertise to set up the system.

Slide 18: Joan

We were also hearing from survivors who had used night-time ventilation since the acute poliomyelitis. Judith introduced you to Susan earlier. One day she called the office: "We went out to dinner last night. I had to make a choice. I could eat or breathe but struggled to do both." She explored her options among friends and IVUN, she talked with her physician, and they decided on the set up you see here, using a PLV-100 for day and the iron lung at night. "They want me to use a mask at night. I tried, but I can't get used to it." She resumed her active life of going to dinner, art shows and film festivals. Listen to your patients. Susan recognized how important it was to use her mind and to that end learned T'ai Chi. Of course, she couldn't move, but she did the movements in her mind.

I heard recently from another iron lung user, Carol, who was looking for a collar for her lung – we happened to have one that was donated to us. When she called to thank us, she told me she uses her iron lung 6 nights a week and on the 7th, she sleeps in her water bed with a mouth piece that she does not drop during the night. "I know I am not as ventilated because I am more tired the next day." I asked, "So, why do you do it?" "I am married."

Slide 19: Joan

Carol and Susan epitomize the concept of independent living. Meet Adolf. I believe he is now using the Astral. He is always looking and trying new things. As you see here, he uses aquarium tubing for his mouth piece. "Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation."

Slide 20: Joan

"Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves ..."
Listen to your patients. They know so much. Many can take credit for the fact they have kept themselves alive.

Slide 21: Joan

The independent living movement began in the early '70s in Berkeley when Ed Roberts, on your right, a polio survivor who slept in an iron lung, wanted to and did attend Berkeley, living at first in the infirmary. Here he is with another polio survivor ventilator user Justin Dart. They were champions for the civil rights of people with disabilities starting with Section 504 of the Rehab Act in 1974. "No ... individual with a disability ... solely by reason of her or his disability, be excluded ... be subjected to discrimination under any program or activity receiving Federal financial assistance....," followed by PL 94-142 now known as IDEA - Individuals with Disabilities Education Act. Stating that "to receive federal funds, states must develop and implement policies that assure a free appropriate public education (FAPE) to all children with disabilities," which culminated in the passage of the Americans with Disabilities Act in 1990.

Slide 22: Joan

People with disabilities celebrate July 26th each year as their civil rights day and to remind others that those rights are not consistently granted. One of the constant struggles for ventilator users is flying. We have advocated and provided educational materials about it over the years.

There appears to be fewer problems today for several reasons. 1) Most airlines have written policies and those who jump through the hoops fly successfully. Vent users may ask for a letter from you or ask you to fill out a form – advocate with them. 2) The manufacturers have certified their most commonly used vents for flying and certify all of their new equipment. 3) The issue of not being allowed to plug in on long flights is negated with the newer vents that have hot swappable batteries. 4) Regrettably, since 9/11 many vent users have just given up flying 5) Airline personnel have seen more and more CPAPs and are less fearful of the equipment. One friend said: "I just tell them it is a CPAP."

Slide 23: Joan

Our message is that Ventilator Users Can Survive the System with Your Help

- * Utilize IVUN
- * Listen to your patients
- * Advocate with your patients
- * and the team you assemble is so important. But there are still major problems with the system.

Slide 24: Judith

This is OSA in Shakespeare, and I have to thank my late husband, Dr. Armin Fischer, who used this in one of his talks.

Henry IV Part 1 → Act 2, Scene 4, Page 22.

PETO

"Falstaff! (pulls back the arras) Fast asleep behind the arras, and snorting like a horse.

PRINCE HENRY

Listen, how heavily he breathes! Look in his pockets."

The rise of sleep medicine and increasing diagnosis of OSA has affected the use of ventilation in people with NM conditions. Unfortunately, the majority of sleep labs are designed to test only for obstructive sleep apnea or maybe central sleep apnea, but not hypoventilation which is the main cause of respiratory insufficiency in our NM friends. Most sleep labs do not use end-tidal CO2 monitors. Often they are given a CPAP unit or put on O2 which does nothing to assist their ventilation and can cause them to end up in acute respiratory failure in an ICU with a trach. Sometimes OSA and CSA are a comorbid condition with hypoventilation, but hypoventilation should be checked out first. When the O2 and the CPAP machine doesn't work, they turn to the Internet and find us.

Slide 25: Joan

Searching the internet, people find us and more calls are from family members and friends of people in the ICU. It is difficult to say, "Sorry, we only network with home vent users."

"...of 5 to 10% of patients who survive a catastrophic illness or surgical procedure but are left with a prolonged (by one definition, longer than 21 days) need for mechanical ventilation... least half are dead within 1 year. Among those who survive, readmission rates are high, most remain institutionalized, and less than 12% are at home and functionally independent 1 year after their acute illness."

We do our best to refer from our *Resource Directory for Ventilator-Assisted Living*. I reiterate the importance of guidelines and consensus statements.

Slide 26: Joan

Today, we are hearing from people with COPD, now using vents more and more, and periodically from people with Obesity Hypoventilation Syndrome.

Slide 27: Joan

A major topic of concern for longtime vent users is the phasing out of ventilators (sometimes caused by the ventilator companies gobbling each other up) and the problems some people have in transitioning to the newer ones. Sherry pictured here recently switched from her iron lung to a trach successfully. Nancy, seen at the right, with her PLV-100, is having a more difficult time switching. As I hope you know, the PLV-100, 102, 102b will not to be serviced after Dec 31, 2014.

Preparing for that, in 2012/2013, IVUN coordinated a series of presentations/conference calls to assist long-time vent users during the transition. (See handout links.) I encourage you to advocate with your patients if they are using obsolete equipment and to utilize IVUN's resources.

I hear people say, and I think it sometimes, too. "What's so hard about switching?" Then I stop and think: we are asking them to change the tried and true device that is responsible for their existence. And, there is mistrust all around. Why? Remember, some of these people for years never drank anything in the morning, because they would be no place for them to go to the bathroom. Why? They hear health professionals say (and these are recent comments): "You couldn't have had polio- those people all died." "You wouldn't want to live 'like that,' would you?" "Oh, aren't you lucky- you have a CoughAssist at home. Our hospital won't buy any for us."

Slide 28: Judith

The change in ventilator equipment mirrors the rise of the home health care industry, the DMEs, and the increasing use of assisted ventilation, particularly the use of bilevel devices. Reimbursement for the older equipment was adequate thru the March of Dimes, but then money got tight. Joan has excellently detailed how the reimbursement changed for polio survivors (see handout). In 1993, there was a scare when HCFA (now CMS) and some physicians and vendors met to discuss a national policy for reimbursement for multiple ventilators. The vendors had to guarantee a working ventilator so the easiest way was to place another vent in the home, aka a back-up vent. (Not to be confused with a backup rate.) That national policy never happened, but people were grandfathered in. Also in 1993 the SS act was amended to exclude CPAPs and bilevel devices with a backup rate from the "frequent and substantial servicing" payment category. They now were reassigned to the "capped rental" category and called "respiratory assist devices" or RADS. But it took many years for this to be implemented. See OIG report, finalized in 2001. Then in 2005, Deficit Reduction Act eliminated the capped rental category, and vent users now can own their

bilevels after 13 months. Next came competitive bidding which often forces the really good mom-and-pop home health care companies who are the experts for our NM people out of business. The complaint is that the larger companies who won the contracts are not licensed to provide this equipment. Major efforts have been made to halt competitive bidding and it is hoped that the market pricing program act introduced last year (which has a 5% chance of being enacted) will be the solution.

Slide 29: Joan

Let me briefly tell you about Helen. Helen was born in 1938 and had polio in 1946, spent a week in an iron lung and another 2 ½ months in rehab. She never walked again, but went to high school and graduated from college with a degree in finance. She learned to drive a van from her wheelchair at age 36 and became the organization's accountant and retired after 35 years in 2005. She received a power chair in the mid-80s and started using a BiPAP at night in 1999. She visited her pulmonologist every 6 months (for years) and was switched to a BiPAP AVAPS a few years ago. She happily used the Breeze with nasal pillows. She lived in a small home with her mother, her father having died decades earlier. Thirteen years ago they hired an attendant for a couple of days a week. Then, her mother died in May of 2011 at age 93. Helen continued living in her home with the aid of the paid attendant. Because of her income, the hours were limited. Her back brace cracked and she intended to but never replaced it. Without her brace, she found it harder to breathe while in her chair, so she spent more time in bed and used her vent more and more. It was more difficult to get to appointments, so she skipped them with promises to re-schedule.

On Saturday, Oct 20, her attendant noticed she was not "acting right." After a few hours, Helen consented and the EMS was called. She was hospitalized and it was discovered she had had a stroke, which affected her left side, so now she had use of her right side above the waist and could move her head. They were ventilating her noninvasively. I was asked to visit her with advanced directives papers in tow, because she had none. By the time I arrived she had been intubated. I spoke with whoever would listen and tried to impress upon them that this was a person who has slept on a vent every night for the last 20 years, and please remember that when trying to extubate her. She had not signed documents of her wishes, but the physician in charge spoke with her and felt she was alert enough and that she made her wishes know to him. About 5 days later, they attempted to extubate her and finally was successful to noninvasive – using the hospital vent. About ten hours later in the middle of the night she starting struggling to breathe and, so the story goes, she expressed to them that she did not

want to be reintubated, or anything else done. They offered "comfort care" and she died a few hours later.

A sad story indeed. What's the point? We at IVUN have heard this story too many times and in 2007 created a document called "Take Charge, Not Chances." It is quite extensive and provides checklists and a form for vent users to complete in preparation for hospitalization. The link is listed in the handout or just look for the "Take Charge, Not Chances" logo on our website. Share it with your patients. Talk with them about their wishes. Do they want to be trached? I know your time is limited, but it is a very difficult discussion for many families. Advocate with your patients. Ask them if they have completed the necessary forms. I can assure you that your longtime patients admire and respect you and your opinions. What you say has a tremendous impact.

The other lady on the screen is Audrey King, who uses night-time ventilation and is an expert frogbreather. She told her experience of being trached and decannulated at a Chest meeting via a video almost 15 years ago. See references: Hospital Tales, from ICU to Homecare: A patient perspective. The video was spearheaded and funded by the team of Dr. and Mrs. Goldberg, Audrey and the Chest Foundation.

She emailed recently, "Fifteen years ago, when I was so ill in ICU, if it had not been for a friend who came in with her knitting and refused to leave until they did what they said was needed (a trach) that they kept postponing day after day because of more "urgent" cases I wouldn't be here today. "

Slide 30: Judith

This is a recent email that is typical of the emails IVUN receives. I'd like to emphasize that when we answer these emails, we include a disclaimer – that we are NOT physicians or medical professionals, but we have learned a few things and know whom to refer people to.

We asked Dr. Lisa Wolfe, chair of the Home Care NetWork, to respond and comment. Here is the case:

"When I was about 6 years old, I had the poliovirus. My right side was partially paralyzed, including the ability to swallow easily. I will be 68 years old in December.

"Recently, I was diagnosed, after two hospital stays, with bacterial pneumonia, COPD and a paralyzed diaphragm on my right side. The pneumonia is cleared up. The COPD appears to be minor (for

now). However, I will have the paralyzed diaphragm for the rest of my life. *I must sleep sitting up* and as you can imagine, all activities are difficult.

"I also have been diagnosed with neuropathy and restless legs. I am on gabapentin and pramipexole for these issues.

Follow up email:

"The info was very useful. I just had a sleep test last night and will have a pulmonary function test in a few weeks. My pulmonary specialist will then determine the course of action. I find conflicting info among the post-polio documentation. Some advocate oxygen and some PLV-100 volumizer. Right now my doctor has me on oxygen. I am trying to stay off oxygen during day to live a more productive life and only use it at night.

"The technician at the sleep study last night said my sats were at 76% while asleep, and put me on oxygen right away. She also forced me to try to sleep on my side as I was cutting off my air passage every time my head bobbed to sleep while sitting up.

"I still can't sleep on my back, but the side is progress. As it should be, because it has been two months since diagnosis of pneumonia, so I should be getting better at least in my left lung.

"Lots of controversy regarding surgery, as well. If you can't breathe well, you can't be put under...so, to make a long story short, I am thrilled with the info you sent and will continue to update you on my progress. When I see the doctor, I will have a list of questions based on the documentation you sent me. I am determined to lead the best life I can, so I will continue to look for answers."

Comments by Lisa Wolfe, MD, FCCP, Chair, Home Care NetWork, ACCP, Northwestern Memorial Hospital, Chicago, Illinois

Any person with a history of polio should have been getting routine lung function testing periodically, and the initiation of noninvasive ventilation should have been done proactively based on spirometry, not waiting for symptoms or a polysomnogram.

I run a sleep lab. The sleep lab, as described in this email, should not be prohibiting people from getting care. There was a misunderstanding about this patient's hypoxemia (low blood oxygen). It was blamed on COPD, when the cause was hypoventilation. (Hypoventilation refers to a condition wherein the oxygen (PaO₂) content in the blood decreases and a marked increase in

the levels of carbon dioxide is observed. This lowered PaO₂ content can cause hypoxemia.) It is a common problem in hospitals. Any person with high CO₂ is claimed to have COPD. They don't!

The use of oxygen is particularly concerning because the patient could retain CO₂ at night with the O₂ and not wake up. My background is both with the Muscular Dystrophy Association and the Les Turner ALS Foundation, and we tell our patients to bring an advocate, usually a family member, with them whenever they come to the hospital. We tell the advocate to tell the nurses that we will not be using oxygen, and if it is put on, to keep taking it off. If the staff can put the O₂ through a noninvasive ventilator, that's fine, but it doesn't go on the nose. As much education as we do, we find that the family advocate is the best method.

Dr. Nick Hill: CO₂ should have been measured before getting a sleep study.

Dr. Wolfe discussed whether patient's lung function is "normal." She guessed that this patient has vital capacity (VC) of 30% but did not have it measured at regular intervals until she complained of dyspnea (shortness of breath or breathlessness).

Question: Should plicating (creating folds in the diaphragm and suturing them in place to reduce mobility of the paralyzed hemidiaphragm) the diaphragm be considered?

<http://www.uptodate.com/contents/treatment-of-diaphragmatic-paralysis>

Wolfe: When diaphragms are at different levels, if diaphragm is not high enough, near the armpit, then surgery with plication may not be effective. How much of this patient's problems are driven by diaphragm? I don't think her problems are driven by the diaphragm, but by a combination of accessory muscles and scoliosis. If this patient were to be plicated, she could end up with a trach post-surgically.

Question: Who and when to plicate diaphragm?

Wolfe: We measure both upright and supine VC. I give the patient a year, and then if patient fails NIV, has dyspnea in daytime, and dysregulation of blood gas, I plicate the diaphragm. But this is not true in this case which is polio.

Question: What about the medications prescribed for the neuropathy and restless legs?

Wolfe: "Restless legs" in a polio survivor is not as it seems. Any condition that affects the anterior horn cells will cause fasciculations to appear in the polysomnogram. Frequently we see people with ALS and post-polio and some diabetics who have fasciculations that are over-read as restless legs.

True periodic limb movements are very common in post-polio but is it truly restless legs syndrome and does it need to be treated? If it is causing insomnia and preventing someone from using NIV, then it should be treated. "But if it is not bothering you, why should it bother me?"

Question: What is your view of cuffed trachs for NMD?

Wolfe: I see no reason for cuffed trachs. There is a disconnect between the disability community who are focused on independent living, and how physicians perceive what a patient needs.

They rarely consider a patient's need for autonomy. They only know how to get the ventilator working with cuff up. My first and most important job is to preserve patient autonomy. Whatever I need to do to get that patient speaking is my top priority. Why don't we have effective communication happening? Critical care physicians don't know how to facilitate leak speech. It is a lost art. Air coming through the cords means patients can speak, it is a form of safety. At night, it keeps a few patients awake but they get used to it. Patients with a cuff need to communicate, they need a voice interface, and voice software or gaze devices that can work for communication.

We also do not use fenestrated trachs due to granulation tissue and bleeding, but a new fenestration trach, the Blom made by Pulmodyne, <http://www.pulmodyne.com/products/acute-care/blom-product-information/> is available that prevents that. The balloon is seated in front of fenestration.

Another big issue in transitioning from older vents to newer vents is that the new ones are super-sensitive leak compensators that can't be turned off for cuffed trachs.

That is one of the problems with people transitioning from the PLV-100. The new vent compensates for leaks and people feel a blast of air which they don't like.

Slide 33: Joan and Judith

Because of the complexity of the medical/physical care and time it consumes, the economic and psychological issues (loneliness, anger, anxiety, depression) of ventilator users are not addressed.

I've often remarked to Joan that we are really social workers as we strive to answer questions and help people find solutions and refer them to the appropriate physicians and economic resources they need. Therefore, who forms your team is critical to ensuring that ventilator users survive the system.

Thank you, Lisa. If any of you would like to be consulted on these cases, please identify yourself to us so we can use you and list you in the directory. All of us can help our vent users.

Thank you for attending.