

IVUN's mission is supported by its Membership.

Max Starkloff and the Fight for Disability Rights

by Charles E. Claggett Jr. with Richard H. Weiss

Joan L. Headley, Executive Director, IVUN

Recently I attended a reading from the book, *Max Starkloff and the Fight for Disability Rights*.

After a C4-5 injury due to a car accident at age 21, he ended up in a nursing home for 12 years beginning in 1963. He received a letter from our founder, Gini Laurie, asking him, "What are you doing in a nursing home?"

Author Charles E. Claggett Jr., marketing vice president at Warson Brands, described the book as the love story between Max and a physical therapist at the facility, Colleen Kelly, who became his life-long partner in marriage and in activism. Barriers to moving out of the nursing home, adopting children, making St. Louis accessible, and more, constantly faced them. Claggett describes the book as a thriller enticing the reader to see how Max removed the next barrier.

I knew Max. He was an already-established leader of the independent living movement when I arrived in St. Louis in 1987. I was on his board (Paraquad) and he was on mine (Gazette International Networking Institute/IVUN) for years.

In the early '90s, our offices were in the same building. On days that I was frustrated with all the work

or finding money or, as he put it one day, "hoping for the time he'd not have to worry if there was toilet paper in the bathroom for staff," I would go up to his office and we'd talk philosophy. I learned from Max that the most important thing is to learn from past mistakes, even laugh about them, and to always keep looking and moving ahead bringing along as many as possible.

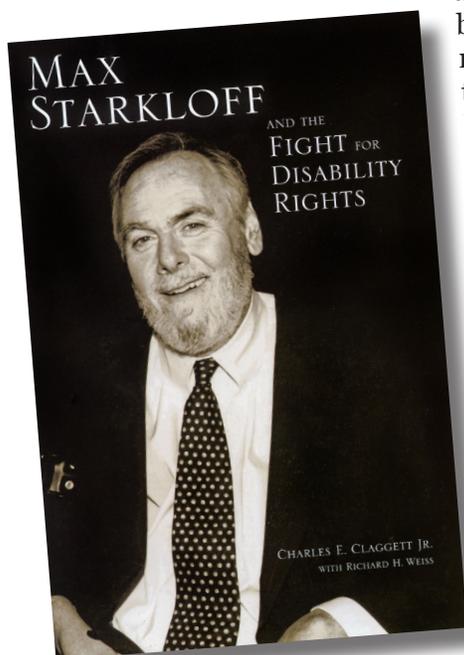
As a quad, he used BiPAP for years and eventually was trached. I recall a

"What are you doing in a nursing home?"

discussion we had about how exhausted he was when he was trying to be weaned from the vent. "I can't do my work." I queried whether being weaned was more important. "I hate the way I sound on the phone using the vent." I assured him that it would get better with practice and it did.

He continued his work for another four years, until he died in 2010. Doing for others what he said Gini had done for him. "I found myself at the table at meetings, thinking how did I get here? She had paved the way." ■

Max Starkloff and the Fight for Disability Rights is published by the Missouri History Museum and can be purchased online at <http://mohistory.org/node/9670>.



Current Flu Season Could be Severe in US

The Centers for Disease Control and Prevention (CDC) urges immediate vaccination for anyone still unvaccinated this season and recommends prompt treatment with antiviral drugs [Tamiflu (oseltamivir) and Relenza (zanamivir)] for people at high risk of complications who develop flu.

So far this year, seasonal influenza A H₃N₂ viruses have been most common. There often are more severe flu illnesses, hospitalizations and deaths during seasons when these viruses predominate.

“It’s too early to say for sure that this will be a severe flu season, but Americans should be prepared,” said CDC director Tom Frieden, MD, MPH. “We can save lives with a three-pronged effort to fight the flu: vaccination, prompt treatment for people at high risk of complications, and preventive health measures, such as staying home when you’re sick, to reduce flu spread.”

Department of Education: Student Data Transparency

The U.S. Department of Education provides guidance to help school districts and educators keep parents and students better informed about what student data is collected and how it is used. The guidance urges districts and schools to be proactive in communicating with parents about data collection practices to help alleviate confusion and avoid misunderstandings. A website has also been developed to provide parents with additional resources and information about their privacy rights.

Equipment

Correction: The pneumobelt is available by calling your area Philips Respironics representative.

Reminder: Philips Respironics announced in November 2009 the manufacturing discontinuation of the PLV[®]-100, PLV[®]-102b and PLV[®]-102. “All reasonable efforts will be made to provide rental units, service, replacement parts and technical support to our customers through 12/31/2014.” The suggested replacement device is the Trilogy.

Looking ahead: CareFusion announced in August 2011 that they would no longer manufacturer the LTV[®]800, LTV[®]900 and the LTV[®]950. The end of support for the 800 and 900 is 10/31/2016 and the suggested replacement is the LTV1100. The 950 date is 12/31/16. The suggested replacement vent is the LTV1150.

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International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

How to contact IVUN

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International Ventilator Users Network (IVUN)

To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.

Moving? Change of address?

Notify IVUN before you move by calling 314-534-0475 or email info@ventusers.org, and tell us your old and new addresses.

Away temporarily?

Send us your second address and dates you will be there and we'll do our best to send you our newsletter.

All-Too-Typical Email to IVUN

with Responses by Norma M.T. Braun, MD, FACP, FCCP

Ombudswoman, Clinical Professor of Medicine, Icahn School of Medicine, Mt. Sinai Health System, Senior Attending, Department of Medicine, Pulmonary/CriticalCare/Sleep Division, St. Luke's-Roosevelt Hospitals, New York, New York

Email: *I had polio at age 18 months and spent six months at Sister Kenny in Minneapolis, Minnesota, in 1948 and received hot baths there.*

Norma M.T. Braun, MD, FACP, FCCP:

Do you recall being in a device to help you breathe, as an iron lung? Is there any information from your parents or the records of physicians who cared for you?

Reply: *No, I do not recall being in an iron lung. No records exist from the General Hospital, nor from The Sheltering Arms for that time period. Mom and Dad never discussed my having had polio, as I grew up.*

Here are excerpts from the only letter I found.

“On October 12 or 13, 1948 you became ill and for three days you were listless, and for about four days you had a fever and Doctor Sisterman gave you 300,000 units of penicillin. Then it seemed you were getting better for you had better appetite and were active. At the supper table on Friday evening, Daddy and I noticed you had difficulty picking up your spoon with your right hand. Your fingers didn't grasp the spoon tightly and you tipped your back to the left and displayed some difficulty raising your arm to put the spoon on the table. ... you were taken to the General Hospital for a spinal tap to see if you had polio. (Polio is in the research stage.) Normally, there is 7-10 white corpuscles each cubic centimeter in the spinal fluid, but you had a count of 72. Soon as the doctor rechecked the laboratory report, you were admitted to the contagion ward.”

* * * * *

Email: *My right side is smaller in circumference and length. My pelvis is twisted and I walk by throwing my left leg inward. I tend to turn in my right foot also, so I try to pay attention to this as I age, as my balance is not good anymore. I can stand on both feet and swing my right foot. The difference in length*

has never kept me from sports. I was never told I couldn't do anything, except contact sports.

Braun: This suggests that you had truncal muscle involvement which may be playing a role now. The twisting you describe can be from a combination of weak truncal muscles and proximal leg muscles especially the quadriceps muscles. There is clearly weakness in the right lower leg muscles as you are compensating by using other muscles to both turn the foot and move it forward.

* * * * *

Email: *About 8 years ago, I was diagnosed with PPS by a neurologist and neurosurgeon in the state in which I now live.*

Braun: Were there any electro-physiological studies? How was this diagnosis made?

What did they recommend?

Reply: *No tests were done. No recommendations were made. My walk showed a limp to the right and I had shallow breathing. The symptoms I expressed over the years I had seen him as a patient led to his assessment.*

* * * * *

Email: *Recently, on a trip to Duluth, Minnesota, to bury my mother, who had told me in the '80s that I snored, I shared a room with double beds with my brother who said I snored so loudly that no matter what he did during the night, he couldn't sleep. In a trip to Hawaii last December 2013, I stayed with friends, in the opposite end of their home with doors closed. They could hear me snoring in their bedroom!*

Braun: What is your age now? What is your height and weight and has the latter changed? When did it change?

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Reply: *I was 5'7" at age 19. In 2012, when I had a total left knee replacement, I found out I was 5'5" tall. I weighed 157 pounds in May of 2014. I then took prednisone for another condition and I gained 25 pounds.*

Braun: This weight gain, from prednisone likely, increases the stress on already weakened muscles and joints. The height loss of two inches may be from loss of water from the discs between the spine bones but may also be due to osteoporosis, made worse by reducing physical activity. If you have developed scoliosis, from the different degrees of weakness on each side, it might also contribute to height loss.

* * * * *

Email: *This past September 2014, I saw an ENT who sent me home with a sleep apnea home study unit for three nights. The outcome was severe apnea (63 apneas per hour) and shallow breathing. I was told that I sleep with an 80% oxygen level in deep sleep. As of this date, approval by insurance for the sleep apnea equipment is pending.*

Braun: Home sleep studies are best for suspected classic Obstructive Sleep Apnea (OSA), not for patients with past polio or other disorders interfering with restful sleep. Carbon dioxide levels need to be measured and can be done noninvasively with end-tidal CO₂ levels. Most standard sleep labs do not monitor CO₂ levels and definitely not home study protocols. (Four months is too long to wait for insurance approval.) A plain CPAP unit may not solve your problems.

Your lung size is determined by your original height of 5'7" and so the loss of two inches "compresses" your lungs rendering them smaller. In addition, your truncal muscles weakness strongly suggests the need for pulmonary function tests (PFTs) with predicted from your original height. This is especially important given the sleep study results.

Reply: *The ENT does not believe a pulmonary test is necessary, because a sleep test proved I had sleep apnea.*

Braun: In reviewing your sleep study results, there is no doubt that you were viewed as a "standard" patient who snores. There were many more episodes where you were hypopneic (shallow) with desaturations, and you had five "central apneas," which means you stopped breathing.

There is no evidence of a physical exam excepting for your height, weight and neck size; giving you a BMI of 30, definitely greater than a healthy 25 or less.

Your neck circumference of 32 cm, which is less than 13", may not contribute to your snoring, depending on your upper airway anatomy.

* * * * *

Email: *As I am a veteran, my counselor suggested that I stay overnight at sleep apnea unit at the VA Hospital. Two hours into the study, the technician said the monitors indicated I had sleep apnea and shallow breathing, and a machine was needed. She hooked me up to a "nose water ventilator" by Phillips.*

I said I couldn't get enough air so she increased the pressure, but after the second increase, I was told I just had "to get used to the machine." During the night, I had to grasp for air and was told to not breathe through my mouth. They diagnosed me with sleep apnea and issued a CPAP.

Reply: *The VA pulmonary physician does not think I need pulmonary function testing either. At present, the Sleep Apnea Section, has urged me to use the Philips Respironics Auto A-Flex machine with the Quattro Air for Her, full face mask. I cough and gag with it, along with gasping for air. They state that CPAP is what I need and tell me that it takes time to get used to CPAP.*

Braun: It is likely that you need a bilevel device. Why? They considered that you needed only a "little" pressure, but when you felt that you needed more air, i.e., a bigger breath, they increased it – "continuously" with the CPAP machine. The need for a bigger breath coupled with your description of your own lifelong

"I said I couldn't get enough air so she increased the pressure, but after the second increase, I was told I just had 'to get used to the machine.'"

shallow breathing strongly suggests that your breathing muscles, the diaphragm and other chest wall muscles have some impairment. This added to your weight gain and the height loss suggests the need for BiPAP – one pressure on inspiration and a lower pressure on expiration.

There is no such thing as getting “used to the machine” when you are that distressed. Your brain is smart and knows what it needs so if the settings are not right, it will be stressful. The unit must be adjusted to you and not you to the machine.

There are many mask types and sizes available now. You may do better with a nasal mask or even nasal pillows where the interface goes into the nostrils. If possible, try until one “fits” like shoes. Masks cannot be used unless comfortable.

* * * * *

Email: *My concentration has been on snoring. I had not thought about having had polio and the residuals that I have had my whole life. I have shallow breathing and I have to take deep breaths several times a minute. I have this action in my mouth that is like sucking on a binky, that I have done my whole life. I have always been weak in my arms. I never thought about restrictions in doing things, until the last several years. Compromise and adjust. It is how I have handled most things.*

Braun: This suggests that you have compensated for the effects of polio with swallowing air into your lungs your whole life and thus not aware that you were different from others since you got polio at such an early age. You cannot swallow air when you are sleeping. It is also more difficult when you are lying down. Further, if swallowing leads to a bloated stomach, then your diaphragms are further “loaded” needing a greater amount of work to breathe.

* * * * *

Email: *What do I do? What do you recommend for me to use to breath at night?*

Braun: I recommend a thorough physical exam of your throat, including soft palate mobility, swallowing, neck, chest wall and diaphragm movements and abdominal and back musculature along with assessment of any scoliosis. The asymmetry of limb muscles along with their strength need to be assessed as well your gait.

Pulmonary function tests are a must in both sitting and supine postures along with maximum static inspiratory and expiratory muscle force as well as a Maximum Voluntary Ventilation (MVV) which is the only test of breathing endurance that is highly correlated with daily function. An ABG (arterial blood gas) sitting and supine for five minutes is also necessary. Predicted PFTs need to be determined from your original height or current arm span.

You need to be seen by a pulmonologist, preferably one more experienced, who may be more willing to research and learn about the late effects of polio. Also, one who is trained in sleep physiology, so he/she might be familiar with more than ONE cause of sleep disordered breathing.

Besides an obstructed airway, sleep disordered breathing can be the consequence of any neuromuscular disorder that affects the proximal muscles. Metabolic disorders (thyroid, diabetes), other neurological disorders (Parkinson’s, dystonias, etc.), medications (prednisone and many others) can all interfere with restful sleep.

This is very serious and needs attention immediately. See *IVUN’s Resource Directory for Ventilator-Assisted Living* on www.ventusers.org. ■

“My concentration has been on snoring. I had not thought about having had polio and the residuals that I have had my whole life.”

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**2nd Joint International Meeting
JIVD 14th International Conference
on Home Mechanical Ventilation
ERCA 5th European Respiratory Care
Association Congress**

When: March 26-28, 2015

Where: Cité Centre de Congrès, Lyon, France

Call for Abstracts: Physicians, nurses, physiotherapists, caregivers and technicians are invited to submit their abstracts on all congress subjects.

Abstracts may only be submitted via the website <http://www.jivd-france.com/jivd/abstract.php>. Selected communications will be accepted for a poster presentation or an oral communication with poster presentation.

Deadline for receipt of abstracts: December 31st, 2014. Acceptance/refusal notifications shall be sent as of February 1, 2015.

The Program (Thursday March 26, 2015, 1:00 pm to Saturday March 28, 2015, 5:30 pm): Designed for physicians, allied health professionals, technicians, manufacturers, equipment suppliers and home care providers, the meeting's session are for those with an interest in respiratory care from the acute setting to home mechanical ventilation.

Healthcare for adults and pediatrics will be covered. Conditions include Neuromuscular diseases (DMD, ALS), COPD, OHS, Central Sleep Apnea, Steinert Disease, Medullar injuries, etc.

Topics include airway clearance, diaphragmatic pacing, NIV 24/7, aerosoltherapy, oxgenotherapy, pulmonary rehabilitation, weaning strategies, NIV in pre and post-operative patients, adapting to worsening LTMV patient, palliative use of NIV and more. Other topics include evolution of home ventilators, home ventilator organizations, telemonitoring, traveling, masks circuits, etc.

The official languages are French and English with simultaneous translation in all rooms.

For program details, registration fees and to register, go to www.jivd-france.com and click on the flag of choice of language.



**14TH INTERNATIONAL
CONFERENCE ON
HOME MECHANICAL
VENTILATION**



**ERCA 5TH EUROPEAN RESPIRATORY
CARE ASSOCIATION CONGRESS**



**8th "A Breath of Fresh Air"
Canadian Respiratory Conference 2015**

When: April 23-25, 2015

Where: Westin Ottawa, Ottawa, Ontario

The Canadian Respiratory Conference is the premier national educational and scientific meeting for the respiratory community in Canada. The program, not yet available, will promote discussion of the most significant developments in clinical practice, research and education. (The deadline for abstracts was October 27th.)

To receive information, contact crc@taylorandassociates.ca or visit www.lung.ca.crc.

FOCUS Spring 2015 Conference

When: May 7-9, 2015

Where: Disney's Coronado Springs Resort, Orlando, Florida.

This conference about respiratory care and sleep medicine features eight different tracks with 18-26 CRCE's and CSTE's, with pre-conference workshops meeting mandatory continuing education requirements, including keynote presentations, food events, exhibit hall and more.

For details see, FOCUS Spring 2015 Conference, <http://focus.com/spring-conference/>.



Families of SMA is now Cure SMA

To acknowledge a “decade of great progress and promise” for the spinal muscle atrophy community, the national group has changed its name to Cure SMA with a commitment to not changing the primary mission of funding new research and providing support to families.

Contact: cureSMA.org, info@cureSMA.org, 800-886-1762

New ALS Handbook

The new *Veterans Health Administration (VHA) Handbook* establishes procedures for health care services to Veterans with Amyotrophic Lateral Sclerosis (ALS). The handbook (VHA HANDBOOK 1101.07) can be accessed at www.va.gov/vhapublications/ViewPublication.asp?pub_ID=3014

In 2008, the VHA recognized ALS as a presumptively compensable illness for all veterans with 90 days or more of continuous active service in the military.

United Spinal Association Launches New Spinal Cord Resource Center

United Spinal Association redesigned and re-launched www.spinalcord.org to connect people living with spinal cord injuries and disorders SCI/D, as well as their loved ones and care providers, to timely resources and support. The site includes tips on numerous subjects and access to a national network of member chapters that support the SCI/D community in many different ways – by promoting health and wellbeing, promoting inclusion and independence, organizing local events and projects, advocating for rights and accessibility, and offering information and support to their chapter communities. ■

Not yet a Member?

Join IVUN for just \$30 a year (Subscriber Membership) and receive your own copy of *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October and December), plus six *IVUN Membership Memos* via email. For \$55 (Subscriber Plus Membership), join IVUN and PHI and also receive *Post-Polio Health* in print four times a year (February, May, August, November) and eight *PHI Membership Memos*.

You can join online at <http://shop.post-polio.org> or send or fax (314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

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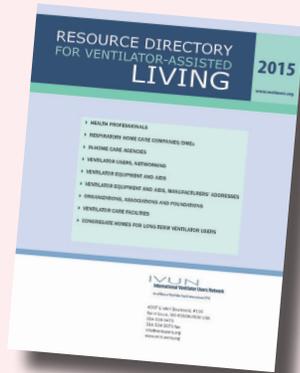
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Resource Directory for Ventilator-Assisted Living Updated

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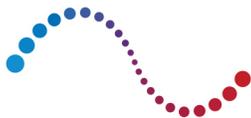


Changes to Ventilator-Assisted Living in 2015

Starting in February 2015, your *Ventilator-Assisted Living* e-communication will have a new look.

Ventilator-Assisted Living (Volume 29, Number 1) will arrive in your email with easier access to articles and with easier ability to share the information.

Having your most current email is important! The newsletter will not be available in print. Note: The newsletter will be sent from info@ventusers.org.



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