



Salk Institute for Biological Studies, La Jolla, California

## Breathing and Sleep Symposium

Joan L. Headley, Executive Director, Post-Polio Health International, Saint Louis, Missouri, [director@post-polio.org](mailto:director@post-polio.org)

The setting was the Salk Institute for Biological Studies designed by architect Louis Kahn. The topics of the November 1 half-day symposium were breathing problems and sleep problems of individuals with neuromuscular conditions and solution options for them.

First to present was Geoffrey Sheean, MBBS, FRACP, Director, Neuromuscular Division, Clinical Professor of Neurosciences, University of California, San Diego. His task was to explain the breathing mechanism and how it is affected by neuromuscular diseases.

People with ALS, muscular dystrophy and post-polio can have new weakness of the diaphragm, the major breathing muscle. For some, throat and tongue weakness can cause obstructive sleep apnea (OSA). For others, the brain fails to send the message to breathe, and central sleep apnea is diagnosed. Sheean's presentation can be viewed at [www.poliotoday.org](http://www.poliotoday.org), a new site created by the Salk Institute.

University of Washington Medical Center, Seattle, Washington, to provide solutions to breathing problems, citing several case studies. Both presentations are available at [www.poliotoday.org](http://www.poliotoday.org).

Lechtzin was challenged to explain in one sentence why using oxygen only is not recommended for people with neuromuscular conditions. It took more than one sentence and bears repeating:

"We all rely on the concentration of CO<sub>2</sub> levels in the blood to stimulate breathing. If someone has weak breathing muscles, he or she may chronically underventilate, which results in a chronically high CO<sub>2</sub>. Over time the ability to sense elevated CO<sub>2</sub> diminishes.

"We all rely to a lesser degree on low oxygen levels to stimulate breathing. However, someone with weak breathing muscles and chronically elevated CO<sub>2</sub> may rely on low oxygen levels to stimulate breathing. If oxygen is given without close monitoring and ventilatory support, the breathing rate may slow, or even stop.

"Most patients with neuromuscular conditions, in the absence of underlying lung disease, don't need supplemental oxygen. If someone has underlying lung disease, oxygen absorption may be hampered and oxygen may be needed but should be added to the bilevel device or ventilator."

Noah Lechtzin, MD, MHS, FCCP, Pulmonary & Critical Care Medicine, Assistant Professor of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland, focused on how pulmonologists determine the cause of breathing problems, i.e., what tests are used, and

on the importance of coughing and other ways to get rid of secretions in the lungs.

Later in the day he teamed up with Louis J. Boitano, MS, RRT, RPFT, Northwest Assisted Breathing Center,



(L to R) Presenters Noah Lechtzin, MD, MHS, FCCP; Geoffrey Sheean, MBBS, FRACP; participant, Raouf E. Yuja, MD.

Photo credit: Sue Lau, Polio Survivors Plus, Orange County, California



Louis J. Boitano, MS, RRT, RPFT, addressing the crowd

Boitano's take-away message was the explanation of a protocol developed by John Bach, MD, and Yuka Ishikawa, MD, to reduce the potential for hospitalization due to respiratory infection. He and Josh Benditt, MD, Northwest Assisted Breathing Center, University of Washington Medical Center, use this protocol with all of their neuromuscular patients who have respiratory limitations.

Under this protocol, individuals are encouraged to buy a finger oximeter to monitor their oxygen saturation level.

Oximeters are available through Internet medical supply companies for about \$60-100. Be sure to purchase one that is FDA approved for human use.

To assure a good reading if circulation is poor, either place hand in warm water or wrap hand in a towel soaked in warm water before attaching the device.

A normal oxygen saturation level is 96-98%. If symptoms of a respiratory infection develop and oxygen saturation falls below 95%, pulmonary congestion may be developing. Individuals should do the following:

1. Use either a manual hyper-inflator or CoughAssist® device to hyper-inflate the lungs and to increase cough support.
2. Increase the use of mechanical ventilation as needed.
3. Contact a physician and request a broad spectrum antibiotic for respiratory infections.

The Northwest Assisted Breathing Center encourages its patients to partner with them in supporting their own respiratory care plan by using both the

home oximetry monitoring protocol and IVUN's "Take Charge, Not Chances" ([www.ventusers.org/vume/](http://www.ventusers.org/vume/)).

Helen Kent, BS, RRT, Progressive Medical, Carlsbad, California, and Diana Guth, BA, RRT, Home Respiratory Care, Los Angeles, California, displayed numerous nasal and face masks, which attendees could try. Several ventilator equipment exhibitors offered a close-up look at a range of assisted breathing devices.

For the meeting, Guth updated her article, "Masks, Part II: Noninvasive Interfaces," first published in 2005. It is available at [www.ventusers.org/edu/valnews/val19-3b.html](http://www.ventusers.org/edu/valnews/val19-3b.html).

More than 150 individuals attended the symposium, co-sponsored by ResMed Corp. and the Salk Institute for Biological Studies. ▲



Masks, masks and more masks. Guth describing an interface to Leslie Smith, Sacramento Post-Polio Support Group.

(L to R) Gladys Swensrud, Co-Facilitator of the San Diego Polio Survivors, who had struggled to receive the appropriate diagnosis and treatment for her breathing problems, was the force behind the symposium. She was assisted by Rick Van Der Linden, PPS Manager. Judith R. Fischer, IVUN Information Specialist, helped develop the program and served as moderator.

Photo credit: Nancy Yates

