

December 11-14, 2006

American Association for Respiratory Care (AARC)

52nd International Respiratory Congress
Las Vegas, Nevada

Lectures will be presented Monday-Thursday, December 11-14, 2006. The Exhibit Hall will be open Monday-Wednesday, December 11-13, 2006. Lectures schedules, housing and travel discount information are available at www.aarc.org.

For Parents and Kids

Barriers to Respiratory Care

Presentations from Parent Project Muscular Dystrophy's 2006 Annual Conference, held in Cincinnati, Ohio, July 13-16, are now available online. Jonathan Finder, MD, discussed breathing in DMD in "Barriers to Respiratory Care for Patients with DMD or ... Creative Use of Outrage in Advancing Healthcare in DMD." Go to www.parentprojectmd.org/site/DocServer/finder_breathing_2006.pdf?docID=1213. Dr. Finder is Associate Professor of Pediatrics, University of Pittsburgh School of Medicine, Pennsylvania.

<http://idea.ed.gov> Launched

The Office of Special Education and Rehabilitative Services (OSERS) and the Office of Special Education Programs (OSEP), at the US Department of Education announced the release of the final Part B regulations implementing the 2004 reauthorization of Individuals with Disabilities Education Act (IDEA). OSERS created this site to provide a "one-stop shop" for resources related to IDEA and its implementing regulations. The site provides searchable versions of the statute and regulations, as well as access to cross-referenced content from other laws, such as the No Child Left Behind Act and the Family Educational Rights and Privacy Act.

Bullying Prevention Site: www.pacerkidsagainstbullying.org

Pacer Center, Minneapolis, Minnesota, has a new website that teaches second through sixth graders what bullying is, how to respond to it, and how to prevent it. Geared for all children, the site includes children with disabilities who can be particularly vulnerable to bullying. ▲

Equipment/New Interfaces

Mojo™ SleepMask™, a new full face mask from The SleepNet Corporation, features a pliable ring and flexible shell for instant customization. A comfortable fit is achieved through a contour shell that easily bends inward and outward. A gel forehead pad stabilizes the mask, and easy-release magnetic clips keep the straps in place. Contact your local home health dealer or SleepNet, www.sleep-net.com.

Hybrid™, new from Hudson RCI, is designed to be a universal interface, used either as nasal pillows or an oral interface, or a combination of the two. Pressure points on the forehead and bridge of the nose are eliminated. Glasses can be worn by the user because tubing does not go up and over the head. Good for mouth breathers, a built-in chin flap supports the chin. Contact your local home health dealer or Hudson RCI Customer Service at 866-246-6990, or visit www.hudsonrci.com. ▲





Jack Quigley, 1987

In Memoriam

JOHN (JACK) L. QUIGLEY, JR., died August 25, 2006 in Mount Pleasant, South Carolina. Long-time members of IVUN will remember Jack as a contributor to the *Rehabilitation Gazette*, where he contributed his experiences of living with a spinal cord injury and using nighttime ventilation. Quigley was a personal friend of Gini Laurie, the founder of the organization, and eloquently honored her at the Fifth International Polio & Independent Living Conference in June 1989, just one month before her death. He served on the Board of Directors of then Gazette International Networking Institute for several years and was its President from 1988-1990.

Ventilator Users' Medical Emergency (VUME) Project Update

“Here’s what we’ve done since our last update:

- Prepared and distributed a questionnaire to health professionals (pulmonologists, physiatrists, respiratory therapists) who are IVUN members and to select health professionals in other associations, such as those in emergency medicine and critical care.
- Interviewed leaders in non-profit associations for persons with neuromuscular conditions such as ALS, spinal cord injury and muscular dystrophy.
- Recruited Robert Casco, PhD, in Iowa City, Iowa, to interview health professionals and to assist with analysis of the data received.

“Our next step is to write the ‘guidelines’ for ventilator users, their attendants and for the health professionals who may treat them during an emergency situation.”



Ginny Brickley, Project Leader

Norma Braun, MD, FACP, FCCP, Retires

IVUN salutes Norma Braun, MD, who retired in July as Senior Attending Physician, Pulmonary and Critical Care Division, St. Luke’s-Roosevelt Hospital in New York City. Dr. Braun writes, “Although I am retiring from private practice, I am trying to set up a neuropneumology clinic at St. Luke’s where I will volunteer to see patients with ventilatory problems due to neuromuscular diseases. This will include all my present ventilator patients.”

Dr. Braun started her internship on the Bellevue Chest Service where in 1963 she first saw the use of noninvasive ventilation: iron lungs for patients with COPD. This spurred her research and led her to the study of respiratory muscle function. Dr. Braun published the first study of the relationship between respiratory muscle strength and the ability to sustain eucapnia (the condition in which the CO₂ tension of the blood is normal).

Dr. Braun has taught at all levels as a clinical professor of medicine at Columbia University; served on medical boards; published more than 50 papers, abstracts, book chapters and e-internet articles; and most importantly, been a strong and ceaseless advocate for her patients.



Norma Braun, MD