

Research Grant to Examine Ventilator Users' Quality of Life

Gazette International Networking Institute (GINI), coordinator of International Polio Network and International Ventilator Users Network has awarded its first GINI Research Grant to a multi-disciplinary research team in Toronto, Canada.

The recipients of the \$20,000 award, funded by the Thomas Wallace Rogers Memorial Respiratory Research Grant, seek to expand knowledge about the factors that impact the health and well-being of people with neuromuscular diseases and conditions affecting breathing (polio, ALS, muscular dystrophy, etc.) who live at home with their ventilators.

The study will be conducted through the Clinical Evaluation and Research Unit and the Respiratory Rehabilitation Program at West Park Health Care Centre. Qualitative research methods will be utilized to document long-term ventilator user perspectives on what they consider to be important for the attainment and maintenance of health-related quality of life. In addition, the team will describe how consumers perceive their quality of life changing as personal living circumstances evolve over time and how this relates to independent living. This knowledge can be used to influence service delivery to reflect consumer priorities as well as enhance the system's ability to meet the expectations of long-term ventilator users.

"Even though mechanical ventilation has been available since the polio epidemics of the 1940s, new knowledge about the consequences of long-term ventilation on the quality of life of ventilator users will provide more insight into these individuals' care," states Martin B. Wice, MD, Medical Director of St. John's Mercy Rehabilitation Center in Saint Louis and President of GINI's Board of Directors.

Members of the research team, led by Mark Tonack, MA, Senior Researcher, Toronto Rehabilitation Institute, and Research Associate, West Park Health Care Centre, are polio survivor and ventilator user Audrey King, MA, Vice Chair, The Center for Independent Living in Toronto; Dina Brooks, PhD, Assistant Professor, Department of Physical Therapy, University of Toronto, and Research Associate at West Park Health Care Centre; and Roger Goldstein, MD, Professor of Medicine and Physical Therapy, University of Toronto, and Director of Respiratory Medicine, West Park Health Care Centre.

"This study reflects GINI's mission of collaboration among ventilator users, health professionals, and researchers through every phase of the project," says Joan L. Headley, Executive Director, GINI. "The outcome promises to provide a crucial link between the ventilator user's perspective and future clinical practice."

Launched in 1995 with a bequest from polio survivor and investment advisor Thomas Wallace Rogers, The GINI Research Fund supports the work of researchers and clinicians investigating the late effects of poliomyelitis or neuromuscular respiratory disease through one of two grants:

- *The Thomas Wallace Rogers Memorial Respiratory Research Grant* to study the cause and treatment of neuromuscular respiratory insufficiency and the effects of long-term mechanical ventilation;
- *The Post-Poliomyelitis Research Grant* to study the cause(s), treatment, and management of the late effects of polio.

The grant award is based on a competitive review of proposals by a panel of research experts, health care professionals, and persons with disabilities.

"Tom would be proud that the first grant recipients are exploring home mechanical ventilation," states Oscar A. Schwartz, MD, Tom's physician for many years. "He demonstrated to me that long-term ventilator users live active, involved lives, but there is more to learn."

Additional contributions are needed to increase the corpus of The GINI Research Fund so larger grants can be awarded. "Contributing to the Fund is an excellent way to honor loved ones," says Headley.

Contributions earmarked for The GINI Research Fund can be sent to GINI, 4207 Lindell Boulevard, #110, Saint Louis, Missouri, 63108-2915 USA. ■

Improving Quality of Life

Traci Lindesmith, RRT, CPFT

The Pulmonary Clinic at Children's Texas Medical Center of Dallas is designed to manage the unique pulmonary problems associated with neuromuscular disease in pediatric patients ranging from newborns to 18-year-olds.

Since opening in October of 1996, the clinic has treated more than 450 children, most of whom are seen at least once annually. The majority of the diagnoses includes spinal muscular atrophy, muscular dystrophy, spina bifida, Charcot-Marie-Tooth disease, and myasthenia gravis.

In the early stages of neuromuscular disease, especially when the children are still ambulatory, the focus is placed on patient education. Since pulmonary clearance becomes more difficult as infection progresses, the staff teaches the children and parents how to recognize the early signs and symptoms of upper respiratory infections.

The respiratory therapist works with families to help them prevent and treat pulmonary infections by using techniques such as assisted coughing, chest physical therapy, and the use of pulmonary clearance equipment, which may hasten the recovery time during a respiratory infection.

When lung restriction becomes more advanced due to muscle weakness, the therapist teaches each child to perform chest wall mobility exercises with an Ambu bag (www.ambuusa.com).

The In-Exsufflator cough machine (www.jhemerson.com) is used to assist children with

cough weakness and pulmonary clearance. On a few occasions, the In-Exsufflator has been used on children in the ICU who are suffering from mucus plugging and lung collapse.

Many of the children have nocturnal hypoventilation and require ventilatory support. Our ventilatory method of choice is non-invasive bi-level pressure support using a nasal mask. A few of the children require full-time ventilation and tracheostomies.

A big challenge for the staff at Children's is trying to fit the smaller children with the correct size nasal masks. Custom masks and headgear are often designed for them. The key for us has been keeping a large stock of various sizes and styles of masks available. Each child is unique, and adequate time should be spent identifying what works best for each one. If a child wears the mask for more than 8-10 hours a day, we usually see some problem with skin breakdown. In those cases, we often give them a soft traditional style nasal mask as well as a low profile style so they can alternate them.

The clinic operates every Thursday afternoon. Patients are seen by clinic director Peter Luckett, MD, and Peter Schochet, MD, pediatric pulmonologists and members of the faculty of the Department of Pediatrics at the University of Texas Southwestern Medical Center. The clinic team also includes a nurse, a respiratory therapist, and a pulmonary function technologist. Patients receive a complete pulmonary evaluation (spirometry, lung

volume, MIP, MEP, peak cough flow, O₂ saturation, and ETCO₂ measurements, sometimes ABGs, always chest X-rays) with each visit.

The clinic also works closely with case managers, social workers, and home medical equipment companies so that the children are provided with the appropriate medical equipment at home. Our case management department makes all home medical arrangements as well as discharge planning, but



11-month-old child being ventilated noninvasively with nasal mask

we often help write letters of support for equipment.

Dr. Luckett, also the medical director for the Respiratory Care Department, says, "Caring for this group of patients was new to us when we started four years ago and it has been very satisfying. They have taught us a lot, and we believe our team approach has improved the quality of their lives." ■

ADDRESS: Pulmonary Clinic, Children's Texas Medical Center of Dallas, 1935 Motor Street, Dallas, TX (Texas) 75235 (214-456-2763; tlindesmith@childmed.dallas.tx.us).

Home Mechanical Ventilation in Finland

Ritva Pirttimaa-Kaitanen

In April 2000, I started as a project secretary at Folkhälsan, a nongovernmental organization offering welfare and health services. I had worked for the Finnish Muscular Dystrophy Association (MDA) for 14 years in respiratory physiotherapy and rehabilitation.

Finland's population is about 5.5 million, and there are about 4,000-4,500 people with neuromuscular disorders. We have 20 large hospitals and people with chronic respiratory insufficiency (CRI) are treated in these hospitals. But the number of patients is counted only in hundreds and the hospitals do not get enough experience. There are about 250 people using ventilators due to CRI. They have neuromuscular disorders, such as muscular dystrophy, polio, or ALS. Most of them are living at home.

The purpose of our project is to set up a home mechanical ventilation centre, maybe two, in Finland. However, we know that all hospitals do not agree with us. They do not want to buy any services outside their own hospital. We are also planning special meetings for physiotherapists and doctors. We will analyze one rehabilitation centre in order to obtain a working model for evaluation of respiratory problems and to get a framework for psychosocial support. At present, we do not plan to build a new hospital or even take over an existing one. We are also discussing tele-medical possibilities.

Noninvasive ventilation is more prevalent in Finland than in other Scandinavian countries; it is tried first. Unfortunately, many people start mechanical ventilation after acute periods with pneumonia or other respiratory disorders. We do not have common evaluation and information systems at the moment, although children have a better situation than adults.

If a person obtains legal status as a breathing paralyzed patient, he or she receives all treatment and services from a hospital. They are provided with a maximum of five helpers, 24 hours per day. The helpers' salaries are paid by the hospital. Many people with this status live at home. However, not all ventilator users obtain this status and must organize their helpers otherwise. Finland does have a Handicap Service law that helps people obtain helpers. These helpers are paid by the social services.

Currently, this is not a subjective right for people – each case must be evaluated by the authorities. The Finnish MDA is working to get a helper system as a right for everyone, with no limits in hours per day. We think that all people should have the same possibilities to get treatment and have equal rights concerning helpers and the opportunity to live at home.

We received money for our three-year project from the Slotmachine Association (RAY) in Finland, and are working in cooperation with the Finnish

MDA and Breathing Paralysis Patients' Association. RAY, one of the largest slot machine operators in the world, was established in 1938. It is unique because the entire annual profit generated by the gaming activities is directly used to finance the work of Finnish health and welfare organizations. ■

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INTERNATIONAL VENTILATOR USERS NETWORK (IVUN)

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What Is Fiberoptic Intubation?

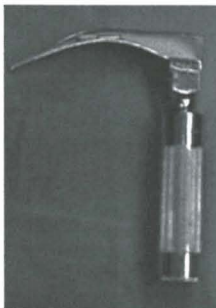
Selma Harrison Calmes, MD

During surgery, when a person needs help breathing, an endotracheal tube (breathing tube) is usually placed in the windpipe (trachea). This insures that all ventilation goes to the lungs and does not inflate the stomach. The tube also protects the lungs from aspiration of gastric contents that can lead to aspiration pneumonia, a potentially fatal situation.

Placing an endotracheal tube requires that the plane of the mouth gets "lined up" with the plane of the windpipe. This means straightening out the usual 90° angle between the mouth and windpipe. Anesthesiologists generally use a metal laryngoscope (see photo) to perform this procedure.

Sometimes this is a difficult procedure with the metal laryngoscope because of arthritis in the neck or jaw, changes from scoliosis or previous surgery, or perhaps from the person's normal anatomy (a receding lower jaw or prominent upper teeth, for example).

To help in these complex cases, anesthesiologists or pulmonologists – the physicians who typically place endotracheal tubes – now can use a flexible fiberoptic (FO) bronchoscope (scope). (See photo.) This device has bundles of very thin flexible glass rods that transmit light from a strong



Metal laryngoscope

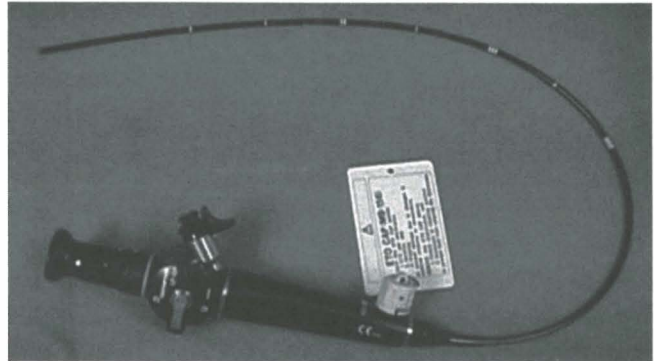
light source and also transmit the image seen at the end of the FO scope. A port for suctioning secretions also travels with the light bundles, and clearing the secretions enables physicians to see better.

The FO scope is very flexible and can easily travel around the sharp angle between the back of the mouth and the windpipe. The FO scope enters the windpipe, and the endotracheal tube is slid over the scope, into the windpipe. The physician can actually see that the tube is in the correct place.

The FO scope can be introduced either through the nose or mouth. Local anesthesia (usually xylocaine or cocaine) is sprayed or placed in the nose, mouth, and throat to make the patient comfortable during this procedure and later when the tube is in place. This anesthesia requires time, up to 20 minutes, to take effect. Sedation may also be administered, but usually this procedure is done with the patient awake, for greater safety. In my experience, most patients have little memory of the procedure.

FO intubation is best done electively, not after failing at regular intubation, because secretions and sometimes bleeding occur whenever working in the mouth or nose and make it hard to see through the scope. Also, the necessary local anesthesia is not as effective.

If your anesthesiologist or pulmonologist recommends FO intubation, there is a good reason. They have evaluated your airway and know there may be difficulty placing the breathing tube. They may also know



Fiberoptic bronchoscope (FO scope)

from the past that you are hard to intubate. The decision to use a FO approach is for your own safety. It takes time to do this properly, especially waiting for the local anesthesia to work. Your physician should tell you what to expect with FO intubation.

FO scopes are very expensive equipment, between \$6,000-\$15,000, but they are worth it. They are now recommended, in the American Society of Anesthesiologists' Difficult Airway Algorithm, for all cases known or suspected to be difficult to intubate. Using this approach has been shown to markedly decrease hypoxic brain injury and death from not being able to intubate during anesthesia, so this new technology is indeed life-saving. ■

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Olive View Drive, Sylmar, CA (California)
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Respiratory Supplies Shopping List

More from Millenium Man Bill Miller

Just in case you wanted to know what a modern day trach positive pressure ventilator user needs for supplies, here's my shopping list. The permanent equipment I own includes two LP10 (Mallinckrodt) volume ventilators; two In-Exsufflator cough machines (J.H. Emerson); and one nebulizer. Because I use the In-Exsufflator, I do not need to be suctioned and therefore do not need any suctioning equipment or supplies. I also have two Passy-Muir "on vent" speaking valves and two Passy-muir "off vent" speaking valves. And, of course, two Ambu bags.

My personal health care system is as cost-effective as any, and more so when you think of the hospital readmissions it prevents. Fortunately, I am covered by private insurance. I order my supplies through a local vendor, RoTech Oxygen and Medical, but provide the vendor with the manufacturer's product number to eliminate the guesswork.

And there is always the little stuff, such as broncho-saline for moistening the airway and secretions, sterile gauze pads for twice-daily trach care, and good old rubber bands to prevent the ventilator circuit from popping off the inner cannula – all these I can buy at the drugstore.

For me, the quality of life provided by the mechanical coughing assistance of the In-Exsufflator (instead of suctioning) is absolutely priceless. My lungs remain clear during most of the day and night. When I do have a secretion buildup, I use the In-Exsufflator for a minute or two, and then I am crystal clear again. I use the device before I go to sleep and sleep straight through for eight hours. Then I may use it again upon awakening. During the day, I use it two to four times, usually after meals. With the speaking valve and my safety net of three hours breathing ventilator-free, I consider the ventilator almost a

Monthly supply order:

- ◆ 4 Portex artificial noses
- ◆ 4 Ballard FLEX (flex-tube with artificial nose)
- ◆ 20 antibacterial filters (Mallinckrodt BARRIERBAC – usually green)
- ◆ 8 ventilator circuits (Allegiance AIRLIFE for PLV®-100/PLV®-102 with the white exhale valve, NOT the red exhale valve)

Every two months:

- ◆ 1 box (10) of Shiley® 15mm snap-lock disposable inner cannulas
- ◆ 1 Shiley® #8 disposable cuffless tracheostomy tube
- ◆ 1 package (5) of inlet filters (Nelcor Puritan Bennett now Mallinckrodt)

Miscellaneous supplies:

- ◆ Portex swivel adapters (blue "elbows")
- ◆ 15mm/22mm adapters (couplings to connect tubing)
- ◆ Dale tracheostomy tube holder (sold in boxes of 10)
- ◆ Shiley tracheostomy tube holder (also sold in boxes of 10)

non-issue. I sleep well and my days are productive. If you heard me speak on the telephone, you would never guess I use a ventilator. ■

ADDRESS: Bill Miller, 9817 Fairway Circle, Leesburg, FL (Florida) 34788 (MaxNWM@aol.com).

Respironics Responds

In response to the article in the Fall 2000 issue of *IVUN News* entitled "UnMASKing the Issue: A Subjective Review of Seven Masks/Headgear" by Audrey J. King, I would like to stress the importance of selecting the right size nasal mask. In the article, the author states, "Our evaluations were limited by the size of mask provided and length of trial." This is an important disclaimer, as proper fit is critical to the comfort and effectiveness of therapy.

Respironics makes every effort to incorporate feedback from users when developing the masks so that they are comfortable and easy to use. Professional home health care providers are trained in mask-fitting techniques. Their expertise can prove invaluable as they work with ventilator users to find the best fit for their needs and to educate them on the features and benefits of each mask type.

To help in mask selection and care, there are three general guidelines to consider. 1) Choose the smallest mask that fits without obstructing the nostrils.

2) Do not over-tighten the mask; loosen the headgear until there is a small leak, then tighten slightly. 3) Maintain mask condition by daily cleaning in mild soap and water. A respiratory therapist should check the condition of your mask periodically throughout the year.

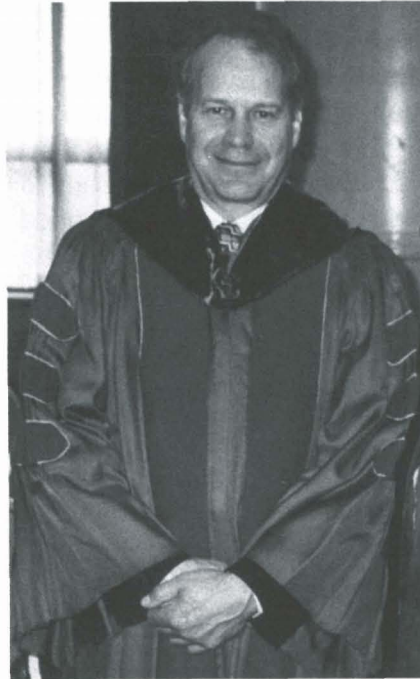
We value input from customers as we develop new technology, and we strive to improve comfort, fit, and ultimately, quality of life. ■

Kristine Sabo, Product Manager
Respironics (800-345-6443;
www.respironics.com)

Dr. Colin Sullivan Honored by ACCP

Colin Sullivan, BSc, MB, BS, PhD, FRACP, FAA, of the University of Sydney, Australia, received the Margaret Pfrommer Memorial Lecture Award from the American College of Chest Physicians at their annual meeting in October 2000 in San Francisco. This lecture was established by Allen Goldberg, MD, and his wife Evi Faure, MD, in memory of ventilator user Margaret Pfrommer who died in 1998.

Dr. Sullivan pioneered the development of continuous positive airway pressure (CPAP) via nasal mask (beginning in 1981) in the treatment of obstructive sleep apnea and later applied the technology, such as the SULLIVAN® Bubble Cushion® Mask and CPAP and bi-level units from ResMed, to people with neuromuscular disease and sleep-disordered breathing.



Dr. Sullivan's lecture "Long-term Nasal Ventilation: Past, Present, and Future" can be ordered on cassette tape from CME Unlimited (800-776-5454; www.landesslezak.com/accp/). ■

Calendar 2001

FEBRUARY 26-28. Children Who Are Medically Complex or Technology Dependent: "Growth Through Transitions."

Philadelphia, Pennsylvania. Contact Ken-Crest Services, Inc., (215-844-4620, ext. 134; kencrest@kencrest.org; www.kencrest.org/medfrag/conf.html).

MARCH 7-9. Eighth International Conference on Home Mechanical Ventilation, Lyon, France.

Journées Internationales de Ventilation à Domicile (JIVD), Hôpital de la Croix-Rousse, Service de Réanimation Médicale et d'Assistance Respiratoire, 93 Grande-Rue de la Croix-Rousse, F-69317 Lyon Cedex 04, France (+33 4 78 39 08 43; +33 4 78 39 58 63 fax; [Brigitte Hautier_JIVD@compuserve.com](mailto:Brigitte.Hautier_JIVD@compuserve.com); www.jivd-france.com).

MARCH 31-APRIL 6. Ventilator-Assisted Children's Center (VACC) Camp, Miami, Florida.

Contact Bela Florentin, VACC, Miami Children's Hospital, 3200 S.W. 60th Court, Suite 203, Miami, FL (Florida) 33155-4076 (305-662-8222; 305-663-8417 fax; www.vaccamp.com).

APRIL 5-7. Focus on Respiratory Care Conference,

Cleveland, Ohio. Contact Bob Miglino, RRT, MPS (800-661-5690; BobM@foocus.com; www.foocus.com).

MAY 2-3. Beyond Ventilation: A Meeting of the Minds.

Toronto Congress Centre, Toronto, Canada. Contact Marg Wagner, Citizens for Independence in Living and Breathing, 55 Greenwood Court, Kitchener, Ontario, N2N 3H6, Canada (519-570-9713 phone & fax; cilb@idirect.com).



Young ventilator users (under the care of Tokyo pediatrician Dr. Yoichi Sakakihara) ready to ski.

New Equipment and Interfaces

OPAP® (Oral Pressure APpliance) is an intra-oral device custom-fitted by a dentist specializing in dental appliances for sleep disorders. It positions the lower jaw forward to maximize the forward movement of the tongue and soft tissues of the back of the throat. The device is simply connected to the end of the hose coming from the CPAP or bi-level unit.

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BiPAP® Synchrony™ is the newest bi-level unit from Respironics. It provides a higher maximum IPAP pressure of 30 cm, as well as adjustable rise times and optional integrated alarms. In addition, it is lighter than the BiPAP® S/T, easier to use, and software can convert it from the S mode to the S/T mode. Contact your local home health care dealer or Respironics (800-345-6443; www.respironics.com).

Breeze™ Sleepgear™ from Mallinckrodt has been redesigned to fit better. It is now offered with the DreamSeal™ assembly which incorporates a nasal mask. Breeze™ Sleepgear™ is still offered with the nasal pillows assembly. Contact your local home health care dealer or Mallinckrodt (800-635-5267; www.mallinckrodt.com). Mallinckrodt also has a website for masks (www.cpapmask.com).

CPAP masks and supplies can be ordered online from CPAP Supplies Plus/Direct, P.O. Box 2038, Orland Park, IL (Illinois) 60462 (877-791-3195 tollfree; 708-403-2776; 708-364-0166 fax; www.cpapplus@aol.com).

VisionKey, is a portable stand-alone communicator that can be connected to a computer (PC or Mac cables are included) to become a full "extended" keyboard. Operates with any standard software, surfs the web, etc.

VisionKey 5+ is the standard model for users with regular eye control with an option for impaired eye control included. VisionKey 5+ uses direct selection or scanning. VisionKey 6V, 6H is the scanning model for users who have definitive impaired eye movements and can move their eyes in one direction only, e.g. locked-in-syndrome. VisionKey 6 uses sequential scan selection. Contact Jan Heynen, H.K. EyeCan Ltd., 36 Burland Street, Ottawa, Ontario K2B 6J8, Canada (800-356-3362 in Canada; 613-860-0333; 613-596-4300 fax; www.eyecan.ca). ■

HMV Workshop

Michael Weinrich, MD, Director of the National Center for Medical Rehabilitation Research at NIH, chaired a workshop "Protecting the Most Vulnerable: A Case Study in Disability and Medical Care" in late October. The goals were to discuss future research regarding home mechanical ventilation (HMV), health policy decisions regarding HMV, and lessons learned from the experience with HMV.

David Gray, PhD, Washington University, reviewed disability and health in the USA. Carol E. Smith, RN, PhD, University of Kansas, presented data on the effectiveness of home care, and Barbara J. Daly, PhD, RN, Case Western Reserve University, discussed critically ill long-term ventilator patients.

Dominique Robert, MD, Hôpital de la Croix-Rousse, Lyon, France, described the respiratory care program in France; Barry Make, MD, National Jewish Medical and Research Center, discussed the home care needs of people using long-term ventilation; E.A. Oppenheimer, MD, appraised the experience at Kaiser Permanente; and John Downes, MD, Children's Hospital of Philadelphia, reviewed their 20-year experience.

Larry Becker, PhD, ventilator user from Virginia, opened the workshop with his personal perspective on the topic. Joan Headley, MS, Executive Director, GINI, presented the issues and obstacles to care for ventilator users based on information collected from individuals in IVUN.

A report will be forthcoming. ■



8th International
Conference
on Home Mechanical
Ventilation

2001 Home Mechanical Ventilation Conference

Lyon, France

ATTENTION: RESPIRATORY HEALTH PROFESSIONALS AND VENTILATOR USERS! This is YOUR conference. If you want to hear about all the aspects of long-term mechanical ventilation from the experts in the field, attend this meeting – the Eighth International Conference on Home Mechanical Ventilation, March 7-9, 2001, in Lyon, France.

The Organizing Committee includes Dominique Robert, MD, Allen Goldberg, MD, Barry Make, MD, and Patrick Léger, MD.

Plenary sessions include ...

lessons from the results of long-term ventilation • chronic alveolar hypoventilation • legal and ethical issues in long-term ventilation • experiences of various long-term ventilation programs around the world • ventilatory support in acute and chronic cardiac insufficiency • acute exacerbation in COPD • coping with severe respiratory disability • long-term ventilation in children, in Duchenne muscular dystrophy, and in ALS.

There are also sessions on practical topics and clinical observations, including ...

technical update in ventilators for long-term care • evaluating candidates for long-term care • interfaces • negative pressure • obesity hypoventilation and sleep apnea syndrome • cystic fibrosis • severe neuromuscular disorders • SCI • tracheostomy • swallowing disorders • secretion clearance.

Ventilator users' sessions are planned for March 7 and 8.

For more information, contact:

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IVUN NEWS

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