

IVUN News

Computers – A Curse, A Blessing, A Necessity

Steve McPherson and Lew Boles

State-of-the-art adaptive technologies with computer chips have greatly enhanced the lives of people with disabilities. If you have a disability and want to live in the community, attend school, work, travel, or volunteer, computer-based technology provides access to and control over much of our functional environment, from augmentative and alternative communication devices to power wheelchairs. Computers give people with disabilities the freedom and flexibility to work in an office or from home. They allow us to compete on a level playing field with our nondisabled peers, as computer programmers, journalists, architects, graphic designers, engineers, lawyers, and social workers, etc. We are only limited by our dreams.

Both of us have been using home computers for over 10 years. There are two types of platforms available – Macintosh and Windows. Today, both operating systems are very similar. They are easily used with a mouse to point and click on icons on the screen and by typing on a keyboard. Certain adaptive devices, like speech or voice recognition, make using the computer even easier.

A voice recognition program for the Macintosh is called PowerSecretary. PowerSecretary (recently discontinued by Dragon Systems) does not have continuous speech, so it takes more time to train your voice to pause between words. Dictating this way may also strain your voice. Users are advised to take regular breaks and sips of water.

A new voice recognition program, MacSpeech, for Mac O/S 8.5 is being developed by the company that started PowerSecretary. It is unclear at this time whether Apple will develop a new voice recognition program as well.

I (Lew Boles) usually have two speech recognition applications loaded into memory at the same time: Dragon Dictate for discreet

There are also on-screen keyboards (Screendoors for the Mac and WIVIK for Windows). Some people who are able to move only one arm or foot can use a track ball.

If you are considering a new computer, the minimum configuration should be a Pentium II or Power Macintosh G3, running at 333 MHz. It should also include an 8



Steve McPherson

utterance navigation and Dragon Naturally Speaking for continuous speech dictation. Keep in mind that the Celeron chip for PCs does not support voice recognition very well.

For people who are more severely disabled, there are head-pointing and eyebrow switch devices that take the place of a mouse. These devices allow users to move the mouse by merely moving the head or lifting an eyebrow. All can be made wireless, usually drawing power from a power wheelchair to provide the user with the freedom of a wireless connection.

GIGB hard drive, 64 MB SDRAM memory, 56K fax/modem, and a 32X CD-ROM drive with a 17" color monitor.

For die-hard Macintosh users interested in learning Windows applications, a G3 233 MHz system, with a 4 GIGB hard drive and 64 MB RAM memory will run Virtual PC with Windows '95 or '98 at Pentium MMX speeds.

You should consider backing up your data using an internal or external Zip or Ditto Drive. For PCs, you will need a 16-bit Sound



Lew Boles

Blaster sound card or 16-bit multi-purpose sound card. Then you will need a high quality inkjet printer. A good rule to follow is, "Buy as much you can afford."

The faster fax/modems use Integrated Services Digital Network (ISDN) – the name for digital telephone service that works over the existing phone line or you can use the same cable your television uses and satellite, but this is considerably more expensive. You will need to check with the service providers in your area.

There are two main reasons to acquire a great deal of power as well as a large amount of memory and storage space: 1) the applications today are fairly large, and more memory and storage allows you to have several windows open at the same time; and 2) speech recognition programs run with a higher percentage of accuracy.

In our personal lives, the computer can serve as a special tool to help keep us organized and to maintain personal communication links. The Internet, and in particular, the World Wide Web have become invaluable resources for gathering information and making decisions. One can plan activities by checking the online *Eye* magazine movie and theatre guide or browsing the CitySearch events

Web site. The Web can be used for making travel plans and bookings on trains and planes. One can manage one's finances via online banking or read an electronic newspaper, magazine, or even a book while waiting for file transfers. With push technology like Pointcast News, activities such as reading headline news, checking the weather forecast, following your favorite sports teams, or trying to complete crossword puzzles are just a click away. There are also specialized applications

that provide digital stereo quality sound for music CDs.

Beyond the Internet software, the personal organizers and information managers can help you stay on top of appointments and remind you about special occasions with interesting pop-ups. They keep you in contact with friends and family using an electronic rolodex of telephone numbers and addresses.

Computers have become vital and indispensable resources and tools. Over the many years we have used computers in their many guises and diversified roles, they remain necessary evils and invaluable friends. ■

For more information on Windows-based computers, contact Lew Boles, 130 Dunn Avenue, # S417, Toronto, Ontario, M6K 2R7, Canada (ortclbo@oise.utoronto.ca).

For more information on Macintosh computers, contact Steve McPherson, 2100 Weston Road, # 807, Toronto, Ontario, M9N 3W6, Canada (cilb@idirect.com).

Steve McPherson. "I first chose a unique type of technology when I was faced with longterm ventilation. Sixteen years ago, as an individual with a high-level spinal cord injury (SCI), I faced the prospect of being tied to a typically cumbersome ventilator. It was not nearly as appealing as phrenic pacers, small electronic devices which are about the size of a Walkman. I chose the Avery Phrenic Pacer from Dobelle Laboratories, the only type of phrenic pacing system available at that time. My two pacers have kept me relatively free from infection; I have had only one small cold in the past four years. The phrenic pacers have even given me the freedom to close my tracheostomy. I use assisted coughing plus frog breathing, and the pacers give me as strong a cough as any adult male, at 8 L per second."

Lew Boles. "I became disabled in 1967 after a football accident caused a spinal cord injury (C4-5). After rehabilitation at Toronto's Lyndhurst Hospital, I moved to Queen Elizabeth Hospital. I transferred to Kingston General Hospital when they developed the technology I needed to learn to access computers. I obtained a B.S. degree in computer science at the University of Toronto and became employed as a junior programmer. Now I work in research and development of Internet computer systems. I have become involved in promoting shared accommodation facilities as an independent living alternative to institutionalization."

Living with Invasive Ventilation

Dan Garrison

Whenever I read about noninvasive ventilation, I think, "Gee, I live with invasive ventilation, and it is no big deal for me." I contracted polio in 1952 at the age of 17. I spent six weeks in an iron lung, followed by a month using a rocking bed.

In 1978 I experienced severe respiratory difficulties. A number of unsuccessful attempts to assist my breathing, including a chest cuirass, were made. I was admitted to the hospital in a very serious condition. It was determined that I was retaining CO₂, and my pulmonologist, after much consultation, placed a tube down my throat and connected it to a ventilator. After 36 hours, the crisis passed. A week later a tracheotomy was performed.

The first trach tube I had was a Shiley plastic fenestrated tube. I used a Mini-Bird ventilator, powered by a large orange compressor. It was quite loud, and I have often wondered why neither my wife nor I went deaf from its noise. Approximately four months after the tracheotomy, my doctor changed the Shiley tube to a Jackson stainless steel tube. By placing a plastic plug in the inner cannula, I could speak with no difficulty.

After six years, I made the transition to an LP4 volume ventilator. Transporting this and the necessary tubing was much easier,

especially with a large metal case that was later provided. Since then, I upgraded to the LP6 and then the LP10.

A few years ago, I switched to a Boston trach tube made of plastic which is quite easy to place in the stoma. The exterior plastic lies smoothly against my neck, over the stoma, with no protrusion. There is an inner cannula that I insert when I need to attach the ventilator.

When I return home in the evening after working as a computer-programmer-analyst, I often lie down to rest and nap and attach the ventilator. I also use the ventilator during the night which aids in preventing underventilation and respiratory insufficiency. I have learned over the years that I need to take precautions whenever I have any kind of respiratory infection.

I have no difficulties living with invasive ventilation. When I am tired or need to sleep, I just hook up and let "mom" ventilator take over the work of breathing for me. I find it easy to watch television from my bed while using the ventilator. There has been some difficulty with my medical insurance company because it does not provide for preventive maintenance of the equipment.

Through the Bruce catalog, I purchased an elastic, washable,

adjustable strap to hold the trach tube in place. The catalog also offers soft, cloth covers (they look like a dickey) to wear around my neck to cover the stoma and trach. I can also wear a tie with no difficulty.

I believe the main reason that I live so easily with invasive ventilation is the time which was taken by medical practitioners in the beginning to talk with me about the tracheostomy and its care. Twenty years have passed since the original surgery, but through trial and error, I have adjusted to the trach. It may not be for everyone, but it is just a normal part of life for me. ■

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Home Care Catalan Society

Joan Escarrabill, MD, pulmonologist in Barcelona, announces formation of the "Home Care Catalan Society." The society involves general practitioners, internal medicine specialists, chest physicians, primary care and hospital nurses, respiratory therapists, and social workers whose goal is promoting home care in Spain.

For more information, contact Dr. Escarrabill, Ciutat Sanitaria i Univ de Bellvitge, UFISS Respiratoria c/Feixa Llarga s/n, L'Hospitalet (jescarra@csub.scs.es).

1999 Camps for Ventilator-Assisted Children

APRIL 5-11. Ventilator-Assisted Children's Center (VACC) Camp, Miami. Contact Bela Florentin, VACC, 3200 S.W. 60th Court, Suite 203, Miami, FL (Florida) 33155-4076 (305-662-8380, ext. 4610).

JUNE 6-12. Trail's Edge Camp, Mayville, Michigan. Contact Mary Dekeon, RRT, C.S. Mott Children's Hospital, University of Michigan, 200 E. Hospital Drive, F3064, Box 0208, Ann Arbor, MI (Michigan) 48109 (734-763-2420).

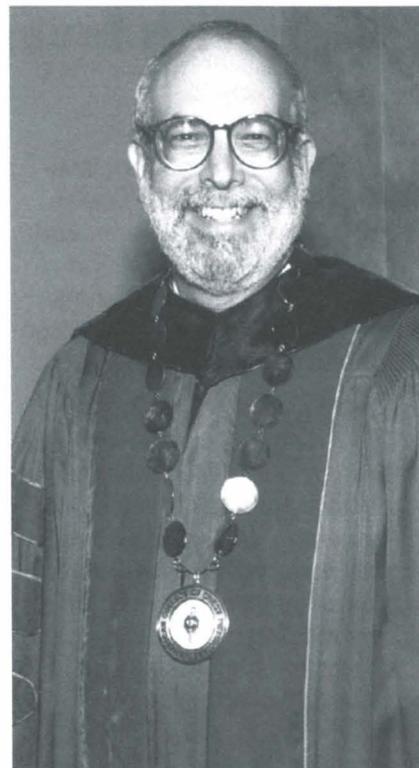
JUNE 13-19. Pennsylvania Vent Camp, Camp Victory, Millville, Pennsylvania. Contact Debra Randler or Michael Dettorre, DO, Pennsylvania Vent Camp, P.O. Box 850, Hershey, PA (Pennsylvania) 17033 (717-531-5337, drandler@psghs.edu, www.collmed.psu.edu/pedsvent).

JUNE 14-18. CHAMP Camp, Recreation Unlimited, Ashley, Ohio. Contact David Carter, RRT, CHAMP Camp, P.O. Box 40407, Indianapolis, IN (Indiana) 46240 (317-787-4555).

JUNE 14-21. Adolescent Retreat for CHAMP Campers 17 years and older.

JULY 4-9. Camp Inspiration, Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children's Hospital, 1056 E. 19th Avenue, Denver CO (Colorado) 80218 (303-837-2502).

SEPTEMBER 2-5. SKIP Camp, Seashore Methodist Assembly, Biloxi, Mississippi. Contact Judy Abney, SKIP of Louisiana, 118 Ned Avenue, Slidell, LA (Louisiana) 70460 (504-649-0882).



Allen I. Goldberg, MD, FCCP, became President of the American College of Chest Physicians (ACCP) in November 1998. Congratulations to Dr. Goldberg, a longtime friend and supporter of IVUN.

Supreme Court Rules in Favor of Teen Ventilator User

In *Cedar Rapids Community School District v. Garret F.*, a case recently decided by the Supreme Court, the issue was: how much nursing care are schools required to ensure are provided to students who are disabled?

Garret, now 16 years old, is a ventilator user due to a high spinal cord injury, who requires frequent suctioning, bladder catheterization, and other assistance with daily health needs.

Garret received special education under the Individuals with Disabilities Education Act (IDEA). The Act's main provision is to ensure

that children with disabilities receive a "free appropriate public education."

When Garret was in the fifth grade, his parents asked the school district to supply him with the health services he needed under the related services requirement of IDEA. IDEA requires school districts to provide needed "special education and related services" to eligible children with disabilities; these do not include medical services.

The school district denied responsibility for the health services, claiming they were "medical," and therefore exempt from cover-

age under IDEA. The parents appealed and won in the lower courts which determined that because the care Garret needed was not required to be provided by a physician, those services were not considered a medical service under IDEA.

On March 3, the Supreme Court ruled 7-2 in favor of Garret. Siding with the 8th U.S. Circuit Court of Appeals, the Supreme Court also concluded that public financing for one-on-one nursing care is required under IDEA, and the exemption for medical services applies only when a doctor's care is needed. ■

Phrenic Nerve Pacing

Phrenic nerve or diaphragmatic pacing is a way to augment diaphragm activity in the work of breathing. Small electrodes are sutured to the phrenic nerves connected by leads to receivers implanted subcutaneously. Radio signals from an external transmitter and antenna activate the receivers, and the stimulating pulses delivered to the phrenic nerve cause the diaphragm to contract, producing inhalation.

All systems must be surgically implanted, but the operation has been streamlined and generally, implants for adults are now in the neck area rather than the chest. A tracheostomy is usually required due to the possibility of upper airway obstruction; often the tracheostomy can later be closed. Several individuals with phrenic pacers also frog breathe.

Candidates for phrenic nerve pacing must have the phrenic nerve intact, as well as normal lung function and normal chest wall compliance. The two groups who benefit most from diaphragmatic pacing are people with high spinal cord injuries (SCI) and children with congenital central hypoventilation syndrome (CCHS).

However, in active children with CCHS, the electrodes can be displaced or fray with movement. Phrenic nerve pacing has not been shown to be effective in people with chest wall deformities, such as post-polio syndrome, but it has been used in a small number of people with COPD.

Three phrenic nerve pacing systems are available (only one – Avery/Dobelle – has been completely approved for use in the United States by the FDA). They are the “Atrostim” Phrenic Nerve

Stimulator manufactured by Atrotech OY of Finland and available from Medlink Technical Corporation in the US, the Mark IV Breathing Pacemaker System from Avery/Dobelle, and Med-Implant, manufactured in Austria and used only in Germany and Austria.

The Avery/Dobelle system, either with unipolar or bipolar electrodes, has been used most widely since its development in the 1960s by Glenn and co-workers (1,000 implants since 1968). The “Atrostim” device has been implanted in 40 patients. It is classified in the US as IDE (Investigational Device Exempt) which must be approved for implantation by a hospital’s Institutional Review Board. The “Atrostim” is quadripolar with the advantage of low frequency stimulation, thus lessening diaphragmatic fatigue. The MedImplant is also quadripolar.

Phrenic nerve pacers improve respiratory physiology because air is drawn into the lungs naturally by diaphragmatic contractions, rather than air forced into the lungs under pressure from a mechanical ventilator. The systems are costly (approximately \$40,000-50,000), but they are covered by Medicare and many private insurers. When balanced against the longterm costs of ventilator equipment, supplies, and care, phrenic pacing systems may be less expensive. ■

SYSTEMS

“Atrostim” Phrenic Nerve Stimulator
Medlink Technical Corporation
1008-A South Pueblo Drive, #108
Taos, NM (New Mexico) 87571
505-751-0133 505-751-0184 fax
riate@taosnet.com

Mark IV Breathing Pacemaker
The Dobelle Institute, Inc.
Columbia Presbyterian Medical
Center
3960 Broadway
New York, NY (New York) 10032-1543
212-927-4000 212-927-6300 fax
inquiries@dobelle.com
www.dobelle.com

MedImplant
MedImplant Biotechnisches Labor
Laudongasse 10
A-1080 Vienna
Austria

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Thanks to the FES Information Center, Cleveland, Ohio, for providing information (800-666-2353 or fes_info@po.cwru.edu).

Let's Hear It for Free Speech!

Sharon Davids, RRT

As a respiratory therapist, I help ventilator users with tracheostomies to speak with the aid of the Passy-Muir Valve (PMV) which enables their speech to be free and uninterrupted.

How does the PMV work? It is a one-way valve that enables air to enter via the trach tube and exit around the outside of the trach tube (cuffless or deflated). The valve may be attached directly to the trach tube, or on the side of an inline suctioning system or swivel adapter. Four models of valves are available, but they all function on the same positive closure principle. The white valve is the original PMV, and more commonly used by non-ventilator users. The clear and purple valves are low-profile, lighter weight, and have a tether which can be attached to the trach tie in case of detachment from the trach tube. They can be used inline with a ventilator using nondisposable, flexible rubber tubing. The aqua valve is designed to easily attach to disposable ventilator tubing and works best inline with a ventilator.

What is the importance of allowing exhaled air to exit around the outside of the trach tube? There are several reasons, but the most important is that ALL of the exhaled air (unless there is leakage around the stoma) is able to pass through the vocal cords to enable speech. And not just any speech, but the speech you would have if you did not have a trach. If you have seen Christopher Reeve on television, you may have noticed that he was speaking while using his ventilator. This is an example of "leak" speech: some of his exhaled air returns to the ventila-

tor, while some of it passes through his vocal cords. He must wait for a breath from the ventilator before he can talk. You may also have noticed that sometimes his voice trails off at the end of his sentences, and he must pause and wait for a breath from the ventilator before trying to talk again. When my patients use a PMV, these leak speech problems do not occur.

There are some research-validated physiologic advantages of using a PMV that I see every day. Many of them are due to positive closure, a patented feature of the PMV which makes it unique among the other speaking valves on the market. This means that a PMV will open easily during inspiration, but it will automatically close at the end of inspiration, causing all of the air to be exhaled past the vocal cords and through the nose and mouth. Thus, NO air is able to leak upon exhalation, creating a normal respiratory sys-

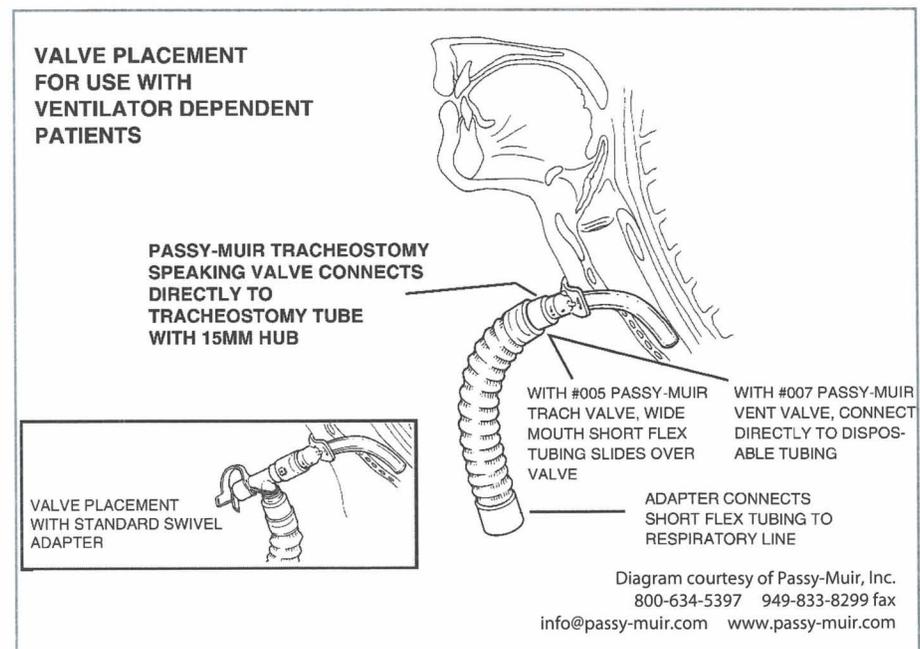


Photo courtesy of Passy-Muir, Inc.

tem, benefiting many actions such as swallowing and coughing.

In swallowing with a PMV, exhaled air is no longer leaking out of the trach tube, but instead is exiting normally via the upper airway. This restores the pressure needed in the pharynx (throat) to facilitate a better, faster, and stronger swallow. And because airflow has been restored in the upper airway, sensation can be increased so that you can feel if something is stuck in your throat, allowing you to cough to clear the throat and protect the airway.

By creating a resistance because the trach is not leaking air on exhalation, there is more force to produce a stronger cough, permitting secretions to be coughed out



of the mouth instead of the trach. When secretions are coughed up, they go around the outside of the trach tube, rather than inside, as a column of air is trapped in the trach tube when the PMV is in place. To allow for adequate space around the outside of the trach tube for comfortable exhalation, you may need a smaller size trach tube.

Oxygen saturation actually increases, as physiologic pressures are restored that allow the alveoli (tiny air sacs in the lungs) to remain inflated at their normal pressure. Again, thanks to no leakage.

With air moving through the upper airway again, senses of smell and taste are improved. A bowel movement is easier, because you can push down harder with your diaphragm.

Decannulation and weaning are faster with a PMV, due to its ability

to restore a more normal physiology to the airway.

A physician's order is necessary to obtain a PMV, and initial placement should be by a qualified health professional, such as a certified or registered respiratory therapist. Changes may need to be made to the ventilator settings to compensate for leaks, usually by increasing the tidal volume and flow rate so that the peak inspiratory pressure is similar to what it was prior to deflating the cuff and placing the PMV. The pressure alarms may then have to be readjusted, especially the low pressure alarm to ensure alarming during a disconnect.

Verbal communication has psychological benefits as well, by enhancing our ability to direct our lives and to enable more active social participation. The use of the PMV is easier and more efficient than anything else I have



PMV in action

ever used, and it has improved the quality of my patients' lives far better than any other device for communication. ■

ADDRESS: Sharon Davids, RRT, Greenbriar Rehabilitation, 9820 Kendall Drive, Miami, FL (Florida) 33176 (dondavids@msn.com).

Potpourri

Ventilator Cart. Designed by a father of a child with CCHS, the EV-1 enables the ventilator and related equipment and supplies to be easily transported. It looks like a baby jogger, with a shelf underneath to hold the ventilator. It is lightweight, folds easily, and is simple to set up and assemble. The EV-S model is for ambulatory children or adults and looks like a cart with shelves for the equipment. For more information, contact Mike Londo at Evolution Karts Inc., 2120 W. Central Boulevard, Orlando, FL (Florida) 32805 (800-683-7109).

Breathe Easy: Respiratory Care for Children with Muscular Dystrophy. Written by Sheila Horan, BS, RRT, Robert

Warren, MD, and Vikki Stefans, MD, of Arkansas Children's Hospital, this booklet discusses Duchenne muscular dystrophy; how it affects breathing; lung evaluation and testing; preventing pulmonary complications; pulmonary management such as incentive spirometry, aerosol and cough therapy; and assisted ventilation, both invasive and noninvasive. Available free from any local office of the Muscular Dystrophy Association or Muscular Dystrophy Association, 3300 E. Sunrise Drive, Tucson, AZ (Arizona) 85718 (800-572-1717, mda@mdausa.org).

Guide to the Evaluation and Management of Neuromuscular Disease (1998; by John R. Bach, MD, FAAPMR, FCCP) presents treatment options

for every stage of neuromuscular disease. ISBN 1-56053-301-3, 186 pages, \$29 (US), \$34 (outside US), softcover. Contact Hanley & Belfus, Inc., Medical Publishers, 210 South 13th Street, Philadelphia, PA (Pennsylvania) 19107 (800-962-1892, 215-546-7293, 215-790-9330 fax, www.hanleyandbelfus.com).

Seventh International Conference: Noninvasive Ventilation - Across the Spectrum from Critical Care to Home Care, March 14-17, Orlando, Florida. Audiotapes of the sessions or a CD-ROM are available. For a list of the sessions and pricing information, contact the ACCP, 800-343-2227 (www.chestnet.org). Some sessions will be transcribed in future issues of *IVUN News*. ■

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IVUN Resource Directory 1998/1999 is an excellent networking tool for health professionals and both longterm and new ventilator users. Sections are dedicated to health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. The cost is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air. (US funds only)

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Children's Medical Center, Atlanta, Georgia. **JUNE 26:** NY Presbyter-ian Hospital-Weill Cornell Medical Center, New York, New York.
AUGUST 14: Vencor Chicago North, Chicago, Illinois. Contact Passy-Muir, Inc., 800-634-5397 or 949-833-8255 (info@passy-muir.com). ■

Seminars, 800-223-5766 (network@speechpaths.com).
Passy-Muir Tracheostomy and Ventilator Speaking Valves: Effective Assessment and Treatment Strategies to Enhance Patient Outcomes (one-day continuing education seminars). **JUNE 12:** Scottish Rite

Calendar 1999

APRIL 21-23. Children with Special Health Care Needs: Implications for Policy, Practice, and Service. Washington, DC. Wyncham Washington Hotel. Sponsored by UMass Memorial Healthcare, Department of Pediatric Pulmonology, National Association of Pediatric Home and Community Care; and the University of Massachusetts Medical School. Contact Dorothy Page, FNP, MSN, 508-856-1908 (dorothy.page@banyan.ummed.edu).

APRIL 23-24. Rehabilitation Approaches for Tracheostomized and Ventilator-Dependent Population. University of Louisville, Kentucky. Offered by Mary Mason, MS, CCC-SLP. Contact Professional Marketing