Adopting Children with Special Needs

Nora Edgar, Gould City, Michigan, neaaskmi@aol.com

Our son, Gabriel, was born with a congenital myopathy which affects his arms, shoulders and respiratory muscles. He has used trach positive pressure ventilation since birth and is fed through a gastrostomy tube in his stomach.

Gabe spent the first four and one-half years of his life in an institution and received excellent medical care, but he lacked stability. He had many loving caregivers, but no one to call "Mom" and "Dad." Gabe had never been outside, except to ride in an ambulance to the doctor's office or hospital.

Although Gabe was legally free to be adopted, we encountered numerous barriers that prevented his placement with us. Because he had a wonderful judge and lawyer, we were finally able to adopt him at 4½ years of age, but it took us two years to get him home.

Gabe came to us severely developmentally delayed; he could only speak a few words. After only a year and a half of living with us, Gabe blossomed. He now talks a mile a minute and is attending a regular kindergarten classroom, learning his letters and numbers. Because of Gabe's past experience, he hated the outdoors when he came to live with us, but now we cannot keep him inside. With his electric wheelchair, Gabe runs in and out, just like any other 6-year-old boy, albeit one who uses an LTV®950 (Pulmonetic Systems, Inc.) ventilator continuously.

In the United States, there are many more children like Gabe living their lives in institutions; children who do not get the chance to live with a family and not because there is a lack of experienced families. Many adoptive families like ours are faced with too many barriers that prevent ventilator-assisted children from finding their "forever families." Medical personnel often become attached to these children and feel the child could not be cared for within a family setting. There are also monetary incentives for institutions in keeping these children. Many social workers are not aware there are families trained and willing to adopt children who use a ventilator, so they don't know where to look or even try to search for one.

Adopt America Network, headquartered in Toledo, Ohio, helps social workers find experienced families that are willing to adopt medically fragile children. Their mission is "to find good families for the children who wait." As a nonprofit organization, Adopt America Network does not charge fees to parents for their services. They have many experienced families who have passed the home study and are willing to adopt ventilator-assisted children.
Call for Proposals for a 2007 Award of $25,000

IVUN has issued its call for proposals for the fourth grant in the amount of $25,000 to be announced in late 2006. Details about the grant application process can be reviewed at www.post-polio.org/resrch.html or received in traditional mail by calling 314-534-0475.

The postmark deadline for Phase 1 is Wednesday, March 1, 2006. (Applicants will be notified by Monday, May 15, 2006.)

The postmark deadline for Phase 2 is Friday, July 14, 2006. (Applicants will be notified by Wednesday, November 1, 2006.)

The Research Fund has awarded three grants to study the consequences of poliomyelitis and/or neuromuscular respiratory diseases. Complete reports on the first two research studies - Ventilator users' perspectives on the important elements of health-related quality of life and Women with polio: Menopause, late effects, life satisfaction and emotional distress - are available online. Go to www.post-polio.org and click on "Research." The final report on the third grant - Dr. Lechtzin's study (see page 3) - is due online by mid-2006.

The Research Fund was established in 1995 by the Board of Directors as a result of a bequest from Thomas W. Rogers, a polio survivor who used an iron lung, a rocking bed and a volume ventilator over his life span. As dictated by Board resolution, The Research Fund awards the interest earned.

Donations to increase The Research Fund can be made online (www.post-polio.org) or sent to IVUN, 4207 Lindell Boulevard, #110, Saint Louis, Missouri, 63108-2915 USA.

Adopting Children with Special Needs

Home study entails a thorough home evaluation by a licensed social worker, including police and protective service clearances (often requiring fingerprints), a marital history, physicals, a philosophical discussion of raising children and discipline, and more.

Adopting Gabe has been a wonderful experience for our family. He has learned how to write his name, he has ridden a snowmobile and a roller coaster, and he plays with his trucks in the sand.

Watching Gabe's smile as he experiences life is worth breaking down all the barriers that prevented him from joining our family.

Gabe and our family pray that every child in the United States living in an institution will be able to enrich someone's family like Gabe did ours.

If your family would be interested in adopting a special needs child, or if you know of a child that needs a forever family, contact Adopt America Network, 800-246-1731, www.adoptamericanetwork.org.
Earlier Use of Noninvasive Ventilation May Prolong Survival

Noah Lechtzin, MD, MHS, Division of Pulmonary and Critical Care, Johns Hopkins University, received International Ventilator Users Network's 2005 grant to study the effects of earlier use of noninvasive ventilation in people with neuromuscular disease, particularly those with amyotrophic lateral sclerosis (ALS). The study results of the question, “Does earlier use prolong survival?” may be applicable to people with other neuromuscular conditions, including post-polio syndrome and muscular dystrophy.

People with ALS may develop progressive weakness of the respiratory muscles and may die from respiratory complications. Noninvasive positive pressure ventilation (NPPV) has been shown to prolong survival in ALS when it is used in people with advanced respiratory muscle weakness. There is evidence that NPPV may slow the decline of vital capacity in ALS, suggesting that earlier use of NPPV may be beneficial.

Expert panels now recommend NPPV when an individual's forced vital capacity (FVC) is below 50% of predicted, but the ideal time to start NPPV remains unknown. The purpose of Dr. Lechtzin's study is to determine whether initiating NPPV when the FVC is closer to normal improves survival, rather than waiting until FVC declines 50%.

Lechtzin and his team conducted a retrospective cohort study of individuals with ALS at a single institution. The study found that people with ALS, who started using NPPV when their forced vital capacity was greater than 65% of predicted, survived approximately one year longer than those who started NPPV with lower FVCs. This suggests that NPPV use may have effects on the respiratory system beyond simply supporting failed muscles. NPPV may result in benefits by resting fatigued respiratory muscles, improving lung compliance, or reducing the hypercarbia/acidosis which can impair muscle contractility.

Dr. Lechtzin (nlechtz@jhmi.edu) presented the results of his study to a packed audience of 900 people during the International Symposium on ALS and Motor Neuron Disease, held in Dublin, Ireland, in December 2005. His final report will be released by International Ventilator Users Network, an affiliate of Post-Polio Health International, in mid-2006.
Care of a Tracheostomy
Larry Kohout, Edina, Minnesota, lkokhout@mn.rr.com
and Tony Nadeau, Saint Louis, Missouri, soberstill@juno.com

Readers who have used noninvasive ventilation for years have reported to IVUN that they have been offered a tracheostomy because of their increased respiratory insufficiency and the need for more hours of breathing assistance. They have asked, “What is a tracheostomy and how do you take care of it?” Two survivors of polio tell how they care for their “trach” to help others who may be contemplating this option.

Tony’s Experience

I contracted polio in Los Angeles in 1948 when I was 13 years old and have had two tracheostomies. The first came six weeks after the initial onset of the mild form of polio when I relapsed into the more severe spinal-bulbar type. When I awakened from the coma two weeks later, I was in an iron lung and had been trached. At that time, being unconscious and a minor, I had no say in the decision. Today, I’m extremely grateful to those who made that decision.

I was transferred to Rancho Los Amigos in Downey, California, and was gradually weaned from the iron lung. The trach tube was removed shortly thereafter. A month later, I was released from the hospital and, even with limited arm and leg strength from polio, I led a fairly normal life – 40 years of marriage, two children and 30+ years in the workforce.

In the mid ’70s, I began to experience new muscle weakness and breathing problems. In December 1984, I ended up in the Emergency Room. My pulmonologist said my ability to breathe had deteriorated to the point where, if I wasn’t re-trached so I could use a mechanical ventilator on a regular basis, I would most likely die shortly. This time it was my decision and a no-brainer. I told him to do it ASAP.

I’ve used three different ventilators with my trach, and currently use a Pulmonetic Systems LTV®800, their volume vent. I use a two-nights-on and two-nights-off routine.

Larry’s Experience

I’m a newcomer to ventilation. Although I was in an iron lung for a short time during my acute polio experience at age 13, I have spent the greater part of the last 52 years denying that breathing problems exist. After 15 months using a BiPAP® at night and after eating meals through noninvasive interfaces, I ended up using Pulmonetic Systems LTV®950 fulltime.

The shift from part-time to full-time ventilation left me unable to tolerate any of the interfaces that I tried. My face and particularly my nose was so sore that it was three months after I had my trach before I could touch it comfortably.

Figure 1. Airflow moving through the fenestration of a cuffed fenestrated tracheostomy tube.
Diagram ©1995 Singular Publishing Group, Inc.
for Communication and Swallowing Management of Tracheostomized and Ventilator-Dependent Adults
by Karen Dikeman, MA, and Marta S. Kazandjian, MA.
Editor’s Note: Trachs can also be uncuffed and nonfenestrated; cuffed and nonfenestrated; and uncuffed and fenestrated. The hole or window is called the fenestration.
Parts of standard tracheostomy tubes include:

- Outer cannula (outer wall of the trach tube)
- Inner cannula (comes in various sizes and snugly fits inside the outer cannula)
- Flange or neck plate

At that time, I had not subscribed to Ventilator-Assisted Living and I am not certain that I knew all of my options. Even now, knowing all of the options available, I am happy with my decision. While I can breathe on my own for 20-30 minutes, essentially I use the vent 24/7.

Tony's Trach Care Routine

Since 1984, I’ve used Shiley® (Size 8) fenestrated disposable trach tubes. (See Figure 1, pg. 4.) This type allows me to talk normally when the trach’s opening is plugged, either with my finger or with a trach cap. When first home from the hospital, I tried to follow the recommended trach care routine I’d learned from my nurses. After a few months, following the strict sterile procedure began to seem extreme, time consuming and expensive, so I changed it. No health consequences occurred and I still use that routine.

My 3-4 times daily trach cleaning technique, depending on accumulated mucus, involves loosening any hard-to-clear mucus from the outer or inner cannula* walls by spraying Ocean Saline solution inside them. I then “heave” up the loosened mucus into a clean inner cannula or use my suction machine. Routinely, I only insert an inner cannula into my trach when cleaning the outer wall or when using my ventilator for the night.

My ENT, Laurence A. Levine, MD, Saint Charles, Missouri, and I agree with changing my trach tube only two or three times a year, which he does in his office.

Several months ago, some nonmalignant growths appeared in my upper trachea wall directly above the fenestration. These growths were very troublesome and very painful when clearing mucus from the tube. After a few attempts to remove the growths, Dr. Levine decided to take a non-fenestrated trach tube and custom cut (with a Dremel tool) a single fenestration hole a bit below where the other holes had been cut. Success! Since then, the growths have disappeared and have not returned.

Larry's Trach Care Routine

While still in the hospital for the tracheostomy, my wife and I were trained in the routine cleaning of the skin around the stoma. This consists of starting next to the stoma and wiping in concentric circles away from the stoma with a single-tipped cotton applicator soaked first in distilled water and then in peroxide. Once the area has been thoroughly washed with peroxide, the same routine is followed with an applicator soaked in plain distilled water to rinse the area. Finally, the area is dried with a dry single-tipped cotton applicator. A fresh, clean drain-sponge is placed under the neck plate and around the stoma, and everything is re-secured with a trach collar. I use the MARPAC One Size Fits All Series soft foam.
Dr. Oppenheimer's* Observations

"Tracheostomy care includes:

- cleaning the external area around the stoma regularly, and then keeping the skin healthy and dry;
- suctioning as often as needed to remove airway secretions;
- removing and cleaning an inner cannula, if the trach tube has one, then replacing the dry clean inner cannula;
- removing the whole tracheostomy tube on a regular basis, then cleaning and drying it before it is replaced; and
- visiting the ENT or pulmonary physician, as needed, to check the tracheostomy and for further advice on tracheostomy care."

Dr. Oppenheimer went on to say, “Tracheostomy care (and tracheal suctioning) should be taught by an experienced healthcare professional. Sometimes it is advised that a trained healthcare professional should do the tracheostomy tube changes. My preference is to train the tracheostomy user and his/her caregiver to do this properly and then be sure that they can give a return demonstration of their skill and competency.

“This has the advantage that a tube change can be done in an emergency, e.g., if the tube becomes blocked or comes out, even on weekends or in the middle of the night. This avoids emergency trips to a medical center, which may result in too long a delay for safety.

“Two or three tracheostomy tubes should be available. I recommend the reusable tracheostomy tubes, and rotate them so that there are always 1-2 clean and dry ones available. However, many people do well using disposable tubes.”

*Editor’s Note: Dr. Edward A. “Tony” Oppenheimer died in November 2005 (See page 9). We are grateful that we were able to obtain his advice for this article.

Within six weeks of the minor surgery to perform the tracheostomy, I was switched from a cuffed trach tube to a cuffless tube. (See comment with Figure 1, p. 4.) Now, I use a Shiley® (Size 8) disposable tube with disposable cannulas. My ENT, Mark Satz, MD, Saint Louis Park, Minnesota, recommended that the tube be changed every three to four weeks. However, I had a lot of difficulty with secretions building up between the end of the trach tube and the wall of the trachea where it would require the suction tube to make a U-turn to get at them. These secretions would bubble when I talked and caused me to cough and choke. Normal lavaging (washing out) seemed to open the airway a little but it would not stay open long. My wife and I finally stumbled on the routine of changing the trach tube daily.

Even though we use the disposable trach tube and inner cannulas, we pull out the tube and replace it with the one from the prior day which has been washed in peroxide, thoroughly rinsed in distilled water, and dried. Pulling out the tube and replacing it with a clean tube seems to break the hold that the secretions that build up between the trach tube and the tracheal wall have on the trach tube. If necessary, I can lavage again and huff out any remaining secretions. We use a pair of trach tubes for two months and then throw them out. Typically, I will change the inner cannula several times during the day as I feel the need.
It is rare that I have to suction anymore, but occasionally there is a need, particularly when I have an upper respiratory infection. I use the Ballard Trach Care Closed Circuit Suction System for adults (Kimberly-Clark REF 22103), a set-up that allows me to suction myself, even with lack of hand strength and dexterity.

When breathing in after a tracheostomy, air passes directly into the trachea and bypasses the nose and upper airway (See Figure 2.) and there is no way to warm and humidify that air. Enter the HME (heat/moisture exchanger), also known as an artificial nose. This little device is a plastic shell containing a spongy material which is very absorbent for moisture that is inserted in the circuit (the hose) right next to the trach tube.

When exhaling, the moisture in the air coming out of the lungs is trapped in the sponge. The next breath of air being forced in from the ventilator passes back through the sponge, picking up that moisture and carries it back in again. The device does work well for about 10 to 12 hours before there is a need to go back on a supply of heated humidified air, though I have known of some people who have used nothing but HMEs around the clock. (The HME that I use is a Hydro Therm with Flex Tube manufactured by Intersurgical, 1853-T.) I replace the HME daily.

My wife and I have now been following these routines for at least three years. I make yearly visits to my ENT and my pulmonologist, A. Stuart Hanson, MD. Both physicians have commented that whatever it is we are doing, we ought to keep on because they have never seen such a fine-looking stoma. Also, I am clearly maintaining my health.

**What Works**

Both of us think that the items outlined by Dr. Oppenheimer are right on the mark. He provided the checklist of items that needs to be accomplished without giving the specific details or the timetable for accomplishment.

Too often, we read or hear that “such-and-such” needs to be accomplished every three months, or “do this every three days.” People are different. Larry was very uncomfortable until he started changing his trach tube daily, and then started feeling great every day. Tony’s routine is markedly different from Larry’s, but it has worked for him for many years.

We feel that the details of a trach routine are peculiar to an individual, and that all trach users need to figure out what works best for them. It may take a while to establish an effective trach routine, so patience is very important. The reward is better breathing and better health overall.
Current Threats to Ventilator Users in Cost-Cutting Proposals from Medicaid and Other Medical Insurance: A Resolution

IVUN's Consumer Advisory Committee,* representing ventilator users with various conditions, took a stand on behalf of fellow ventilator users in reaction to the ongoing threats of drastic cost-cutting in Medicaid and other medical insurance. The Resolution, endorsed by IVUN's Board of Directors, has been endorsed by 670 individuals. (See complete text and list of endorsers at www.post-polio.org/ivun/res.html)

The Resolution is a statement of philosophy proclaiming "the basic rights of ventilator users to live, to be healthy, and to remain free in the community as contributing members of society." It addressed the fact that "some states, under pressure to reduce Medicaid costs, are formulating or adopting policies that would either deny payment for ventilation devices or would require ventilator users to enter nursing facilities in order to keep or obtain such equipment." It further noted that "those new policies are contrary to the US Supreme Court's Olmstead decision, which upheld the right of people with disabilities to live in the least restrictive setting appropriate to their needs, ruling that unnecessary institutionalization violates the Americans with Disabilities Act."

The Resolution calls for government officials, policymakers and advocacy groups to be guided by principal of the least restrictive setting, and that ventilator users be invited to participate in the development of Medicaid and other health-related policies. The group encourages policymakers to redirect Medicaid cost-cutting efforts to the prevention of bureaucratic waste and provider abuse.

IVUN's Resolution, with accompanying signatures, was sent to: President George Bush; Michael Leavitt, Secretary of Health and Human Services; Mark McClellan, MD, PhD, Centers for Medicare and Medicaid Services; Vice Admiral Richard Carmona, Surgeon General; sixteen governors, including the members of the National Governors Association Medicaid Working Group; and the National Council of State Legislatures.

Responses have been received from the governors of Iowa, Tennessee and Virginia, and can be read in their entirety on IVUN's website, www.post-polio.org/ivun.

*IVUN's Consumer Advisory Committee Members

Lawrence C. Becker, Chair, Roanoke, Virginia
Mark J. Boatman, Jamestown, North Dakota
Deborah Cunningham, Memphis, Tennessee
Richard L. Daggett, Downey, California
Mary Garrett, Queensbury, New York
(parent of vent user)
Ola Grind Hermo, Røros, Norway
Laura Hershey, Denver, Colorado
Audrey J. King, Don Mills, Ontario, Canada
Larry Kohout, Edina, Minnesota
Bill Miller, Leesburg, Florida
Adolf Ratzka, Stockholm, Sweden
Barbara Rogers, New York, New York
Tedde Scharf, Tempe, Arizona
Kimyo Sato, Sapporo City, Japan
Sandra Stuban, Fairfax, Virginia
Home Ventilator Guide is IVUN's latest resource compiled by Judith R. Fischer. The comprehensive resource displays technical information about the world's home ventilators in charts that are easy to read and makes comparing home ventilators more convenient. It features bilevel positive airway pressure ventilators, volume-cycled ventilators, pressure support ventilators, and combination or multi-mode ventilators.

The Home Ventilator Guide was made possible by a bequest from ventilator user Ira Holland. The guide also contains quotes from consumers about some of the ventilators, in acknowledgement of Ira's life-long commitment to advocacy on behalf of his fellow ventilator users to help improve ventilator technology.

The guide is available on IVUN's website (www.post-polio.org/ivun) in pdf format. Members without Internet access may request a copy from IVUN (314-534-0475).

Fischer Steps Down

Judith Raymond Fischer is retiring as newsletter editor of Ventilator-Assisted Living, but will assist through a transition period and will continue to serve as an Information Specialist.

Called IVUN News until mid-2003, the newsletter began as a vision of the organization's founder, Gini Laurie. Fischer, with her eye for detail and her insistence on the facts, provided the dedication and skill to make the quarterly newsletter a reality. Fischer, who has edited this publication since 1989 as a volunteer, became involved with the organization in the late '60s when it was coordinated out of Laurie's home in Chagrin Falls, Ohio. In 1987, she married D. Armin Fischer, MD, a pulmonologist to many polio survivors in Southern California, and moved there after serving as the organization's Executive Director for more than three years in Saint Louis. Dr. Fischer died in 1997.

In Memoriam:
Edward Anthony “Tony” Oppenheimer, MD, FCCP (1937-2005)

Dr. Tony Oppenheimer died of complications of multiple myeloma in November 2005.

Many people knew Dr. Oppenheimer through his extensive email communications on respiratory matters related to neuromuscular disease, begun after he retired in 2000 as Chief of Pulmonary and Critical Care Medicine, Southern California Kaiser Permanente Group. Others experienced Dr. Oppenheimer firsthand as their superb physician at Kaiser, while many knew him as a delightfully philosophical and engaging friend, colleague and mentor.

As a member of IVUN’s Medical Advisory Committee, Dr. Oppenheimer provided thoughtful and comprehensive contributions to IVUN publications and careful review of its pulmonary articles. He understood the technology and the power of the Internet early on and utilized it to the fullest to educate other health professionals about assisted ventilation. He worked diligently, but gently, to educate ventilator users and their families, to ensure that they became accepted as equal partners in the decision-making process about the use of assisted ventilation in the home.

Professionally, Dr. Oppenheimer was Associate Clinical Professor of Medicine at UCLA's School of Medicine, and a member of the California Thoracic Society, the American Thoracic Society and a fellow of the American College of Physicians and the American College of Chest Physicians.
The Christopher Reeve Foundation (CRF) awarded a $20,000 Health Promotion grant to Post-Polio Health International, including International Ventilator Users Network, to explore and address the problem of inadequate or inappropriate treatment of adult users of home mechanical ventilation in emergency situations.

The grant’s plan calls for the involvement of ventilator users and their caregivers or medical advocates, and health professionals. Virginia Brickley, the project leader, will launch the work within a few weeks. Watch www.post-polio.org/ivun for details and/or send your email to ventinfo@post-polio.org with a request to be included in the initial gathering of information about the problems adult ventilator users face in the time of a medical emergency.

“While we know it is not practical to hand a brochure to a physician in the ER, we do believe that creating ‘do's and don’ts’ targeting ventilator users, their families and medical advocates, their health professionals and ER and EMS professionals will decrease the number of medical emergencies that result in severe complications or death,” states Joan L. Headley, Executive Director of Post-Polio Health International.

The Health Promotion grant, a special category of the CRF Quality of Life grants, is funded through a cooperative agreement with the Centers for Disease Control and Prevention. The Quality of Life grants program was conceived by Dana Reeve, Chairman of the Christopher Reeve Foundation and Co-Founder of the Christopher and Dana Reeve Paralysis Resource Center, to help people with living with paralysis in the “here and now.”

PHI's grant was just one of 86 awards given in this cycle totaling $581,034. The CRF also recently gave $100,000 to five Gulf Coast charities in the immediate wake of Hurricane Katrina.

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**ComfortFull™ 2 Full Face Mask** (www.Respironics.com)
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Four points of attachment between the mask frame and headgear for stability; air vent directs air away from wearer and partner; one hand is needed to adjust the forehead support to one of four positions; available in standard, large, shallow and shallow-wide.
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The mission of International Ventilator Users Network, an affiliate of Post-Polio Health International ... is to enhance the lives and independence of home mechanical ventilator users through education, advocacy, research and networking.

Calendar
APRIL 20-22, 2006
6th Annual Focus on Respiratory Care & Sleep Medicine Conference
Opryland Hotel & Convention Center
Nashville, Tennessee
For registration details, including information about continuing education credits for respiratory therapists, sleep technologists and nurses, access www.focus.com or contact Bob Miglino, RRT, MPS, FOCUS Publications, Inc., 22 Parsonage Street, Rhinebeck, NY 12572, 800-661-5690, bobm@focus.com.

IVUN’s Resource Directory for Ventilator-Assisted Living identifies health professionals and ventilator users who are knowledgeable about long-term ventilator use, ventilator equipment and interface manufacturers, and related health organizations. Its production is supported by Dale Medical (www.dalem.com) and Televisit 100 (www.televisit.com)
To obtain a printed copy (34 pgs, $8/US, $12/outside US), contact IVUN, or visit www.post-polio.org/ivun/d.html.

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Christopher Reeve Foundation Funds Received

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