

IVUN News

The Polish National Center for Home Mechanical Ventilation in Children

Marek Migdal, MD, PhD, and Tadeusz Szreter, MD, PhD, DSc

The Polish National Center for Home Mechanical Ventilation in Children was established in June 2000 as a common project of the Polish Ministry of Health and the Department of Anesthesiology and Intensive Care of the Children's Memorial Health Institute (CMHI) in Warsaw. The aim of the project was to collect epidemiological data on chronic respiratory failure in children in Poland, to improve the survival and quality of life in ventilator-dependent children, and to evaluate medical, psychological, and economic outcomes of long-term home ventilation in the Polish pediatric population.

The CMHI is a pediatric tertiary center specialized mainly in cardiology and cardiosurgery, transplantation (livers and kidneys), neurology and neurosurgery, endocrinology, metabolic disorders, and rehabilitation. In our 10-bed PICU, we treat approximately 300 children each year.

Until the middle of the '90s, all children with chronic respiratory failure had to remain in our PICU on ventilation for months, even years. In 1995 we started to treat at home using Puritan Bennett's Companion 2801® ventilator on two ventilator-dependent boys. In 1998 we started to use another method – the implantation of the phrenic nerve stimulator. Until now, five children have been treated using

phrenic nerve pacing; two are still alive.

Our first scientific publications on the national level and mass media reports about children suffering chronic respiratory failure caused a lot of demand for home treatment from parents and other PICUs. Thus, in June 2000, the Polish Ministry of Health decided to begin a project



Kinga at home

of home mechanical ventilation in children with a budget sufficient for 11 ventilators.

During the first four months of the project, 36 requests from regional PICUs were received. All of them met our main inclusion criteria: known final diagnosis, stable clinical state, tracheostomy, ventilator-dependent longer than six months, and readiness of parents for home care. The causes of chronic respiratory failure were mainly spinal muscular atrophy, diseases or injuries of the spinal cord, or congenital muscular dystro-

phies. The duration of previous mechanical ventilation varied from 7 to 36 months.

The order for the ventilators was completed during September 2000, after selection of the Breas PV 401 ventilator. The first patient, a 2-year-old girl with spinal muscular atrophy, was admitted to our PICU two weeks later. The multidisciplinary team (physicians, nurses, respiratory therapists, and psychologist) were involved in the assessment of the parents' ability to perform home care.

While in our PICU, each child is ventilated using the Breas ventilator in the PCV mode. Parents are trained in chest physiotherapy, suctioning, tracheostomy tube change, cardiopulmonary resuscitation, and use and maintenance of the ventilator as well as additional equipment such as pulse oximeter, mobile suction unit, and Ambu bag. Duration of hospitalization in our PICU needed for the child's observation and parents' training varies from 5 to 14 days.

Before discharge home, signed and informed parental consents, as well as agreements with the regional PICU for emergency admissions, are collected. Upon discharge, the children return directly to their homes (up to 500 km away from Warsaw) or are transferred back to regional PICUs.

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Among 14 children already enrolled in the project, 10 are currently at home, two died at home, and two are waiting for ventilators at regional PICUs. Children who are at home are under the care of family doctors, however, we visit them every three to six months. First results confirmed that home ventilation is safe and effective.

The need for antibiotic use because of respiratory tract infections has been significantly reduced (less than one treatment per child during the last six months). None of the children released home have had to be readmitted to the hospital.

Current major problems are slow progress, financial problems of parents, and lack of clear national regulations. Slow progress is mainly due to the high number of acute cases in our PICU. Delayed discharge home is linked to the financial problems of parents. Only the home ventilator is provided by the CMHI, and additional equipment must be purchased by parents or charity funds. Funds for disposable supplies needed for the home care are refunded by only a few of 17 independent regional funds.

Despite all of these problems, we expect that home care for

ventilator-dependent children will continue to grow in Poland. Using the additional funds from the Ministry of Health as well as from private sponsors, we plan to increase the number on home ventilation during 2001 to 20 children. We hope that through our project all of them will be safely and effectively managed at home for a long period. ■

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Success

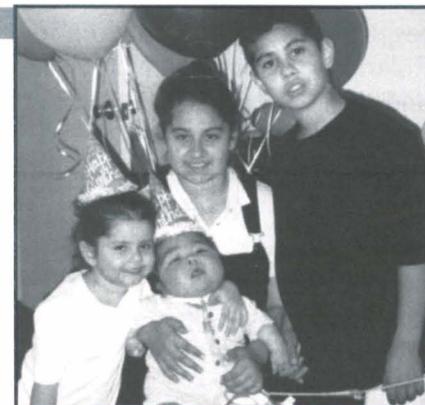
Sheila Kun, RN, MS

How do you measure success? How do you know your program is working? After 20 years of working with children using long-term home mechanical ventilation (HMV), I am asked these questions often. With more than 270 children who have "graduated" from our program and more than 170 children and young adults still actively managed, it is difficult to determine what criteria to use to measure the outcome of the program. Do we count the number of college graduates? Do we count the lower number of hospital readmissions?

Our population represents half of the total number of children using HMV funded by the State of California, and it seems that we should be able to present statistics to quantify our success. But it is the human side of the

equation that is the best measurement. Here is one story written by Natalie, the 13-year-old sister of Christian, one of our ventilator-assisted children. Christian, born with hypochromdroplasia and type II collagen synthesis defect, has surpassed all his physicians' expectations.

"When my baby brother was born, the doctors did not expect him to live, and they let me go with my parents to visit him in the NICU. I saw him with a tube down his throat attached to a machine, lots of medicine hanging from an IV pole, wires coming out of his belly button, and wires attached to his chest. It seemed like a nightmare. I looked at my parents and saw how strong they were, a smile on my mother's face. She said, 'Isn't he cute?' I had to look again, to see what my mother was seeing. Looking past all the wires, I saw the cutest little



Christian celebrates an earlier birthday with his brother and sisters.

thing, and I smiled. From that moment on, I felt peace and knew everything was going to be all right.

"My brother Christian is now 4 years old. He uses a ventilator and oxygen. The most important thing is that Christian is still alive and home with us. He smiles, he is bratty, he is home-schooled, and he is still the cutest little thing."

How do we measure success? One child at a time. ■

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Pediatric Noninvasive Ventilation

Several pediatric respiratory physicians, nurses, and therapists summarize the use of noninvasive positive pressure ventilation (NIPPV) in their pediatric programs.

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Finding a comfortable interface is one of our biggest problems. There are so few made for children. We use only commercial masks, especially Respironics' Simplicity™ and Gold Seal™ masks.

Another problem is cost. It is difficult to justify several types of expensive interfaces when we do not know whether the infant or child can even tolerate CPAP or bilevel ventilation. One mask may cost more than \$100, and then we discover that no matter how comfortable the mask appears, the child does not want it (or anything) on his/her face.

We have tried some infants on NIPPV, but with little success. Again, the interface is our biggest obstacle. The youngest patient whom we have been able to keep on NIPPV for chronic use is 3 years old.

The machines with which we have had success are Respironics' BiPAP® Synchrony™ and BiPAP® Vision™, the Sullivan® VPAP (ResMed), and Puritan Bennett's LP10.

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Our children use commercial masks – the petite sizes in the Sullivan® nasal mask (ResMed) and Monarch™ (Respironics). Some of the parents especially like the gel masks. One mother, whose 5-year-old has CCHS and was recently decannulated,

tried a larger mask to cover both his nose and mouth. Almost all of our ventilator-assisted children use the LTV950™ (Pulmonetic Systems). Some still use bi-level units, either Quantum® PSV or BiPAP® Vision™ (Respironics). I prefer the LTV series – their size, ease in programming, and use in pressure support and CPAP modes. However, they are expensive, and if the children just use them at night, some insurance companies will not cover them. One little boy switched from tracheostomy to noninvasive ventilation very comfortably using the LTV.

Another little guy, born with bilateral diaphragmatic eventration (no functional diaphragm) uses the NEV-100 and Porta-Lung (Respironics). He used to need it up to 16 hours a day, but now, at the age of 2, uses it only at night. It works well, but it is not very portable. There are a few children with SMA who also use the Porta-Lung at night. One uses a combination of Porta-Lung and bi-level unit.

I think that noninvasive ventilation definitely has a place in pediatrics, but it is sometimes more labor-intensive than a stable tracheostomy and less comfortable for the younger children at least. Children who need more ventilatory support than naptime and sleep are more transportable, active, and comfortable with a tracheostomy. When you deal with medically fragile children, management is everything. I view these children as normal and the technology as supportive, and make the machines work

for the child, not the other way around.

One more caveat about bi-level units – some of our children have enough muscle weakness so that their vocal chords do not work well and they are at high risk for aspiration. When you begin pushing high pressures through their upper airway, you can make the aspiration much worse. The downside of negative pressure ventilators such as the Porta-Lung is that some children, especially

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International Ventilator Users Network

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German Pediatric Masks

Uwe Mellies, MD

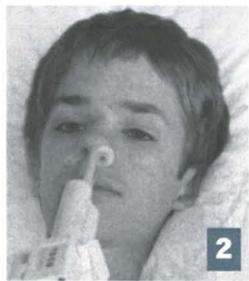
In our programme, 40 children, adolescents, and young adults with congenital neuromuscular disorders use noninvasive mechanical ventilation. If possible, we prescribe commercial



masks. If they do not fit or the child needs a mask without

dead space, a dental technician makes a custom mask (photo 1).

Twelve are using the Mirage® (ResMed) or Gold Seal® (Respironics) nasal mask, 12 are ventilated with the Mirage®



Custom nasal mask being molded of silicone



full face mask, 6 use a custom-made nasal mask, and 10 use a custom-made full face mask.

The custom masks are made of silicone by the dental technician from an individual impression of the child's nose or face (photos 2-4). The final mask is made from this impression, and it can be brightly colored. The process takes about two days but in an emergency it is also possible to build a simple mask at bedside.

These masks are comfortable and fit to our patients with facial dysmorphism. When mouth leak is a problem, we use a full face mask. The masks have no dead space. Triggering the ventilator becomes easy even for children with low tidal volumes.

Unfortunately, silicone and the production costs are rather expensive: a nasal mask (photo 5) is about \$400 and a face mask about \$600, but reimbursement has never been a problem for us. (For more details about the mask, contact Mr. Kruck, AirTec Beatmungshilfen, Mülheim an der Ruhr, Germany, info@beatmungshilfen.de)

All our patients except two are using pressure preset ventilators: Sullivan VPAP® II (ResMed), Helia (Saime), BiPAP® Synchrony™ and Quantum® PSV (Respironics). ■

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those with neuromuscular disease, may have positional upper airway obstruction. They may need to wear a soft collar while they are in the Porta-Lung or need a hi-flow nasal cannula to keep their upper airways stented open.

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Twenty-five paediatric patients use noninvasive ventilation. The most commonly used mask is Respironics' gel mask; however, some children use Puritan Bennett nasal pillows. We use CPAP units and a wide range of ventilators: Breas PV 401, PV 102, and PV 101, BiPAP® S/T 30 (Respironics), Pulmonetic Systems' LTV1000™, and Nippaed (B&D Electromedical).

We select the equipment to suit our patients, and therefore are unable to standardize to one supplier.

Georgiana M. Sanders, MD

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Most of our children use commercial masks. We would like very much to obtain infant masks. However, we do make some custom masks, particularly for children with degenerative muscle disorders and molding problems secondary to this. Our children with noninvasive ventilation almost all use BiPAP®. We are using the LTV950™ often (the LTV1000™ in-hospital only) because it enables us to send home children (particularly babies) who have significant pressure requirements. Also, since BiPAP®

via trach is not approved by many insurances or the FDA, we are using the LTV to provide bi-level treatment for many trach patients. The LTV950™ is very flexible, but there is concern that it is not as reliable as the LP10.

Jim Ripka, RRT

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We use only commercial masks, primarily Respironics, alternating between the gel seal masks and nasal pillows to avoid skin breakdown. We plan to try the small nasal mask from Hans Rudolph.

For ventilators, we use BiPAP® and LP10s. We are starting to use the LTV™ ventilators, but the increased cost of the LTV over the LP10 and the justification required for insurance reimbursement make them harder to acquire. So far both we and the parents like them. They are generally ordered for ventilator-assisted children at home who require PEEP. One thing we will be watching is the durability of the LTVs. The LP10 has been a very reliable ventilator over the years.

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We generally use the masks from Respironics and ResMed as well as their CPAP and BiPAP® machines. There are difficulties in finding the mask that can be best fitted to an individual patient, especially the young ones. We cannot make custom masks by ourselves. In Thailand, not all sizes and shapes of masks are available. If noninvasive ventilators become more popular, we

hope there will be more masks to choose from.

Judith Green-Latner, RN, MSN, FNP

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There are currently 59 children in the Home Mechanical Ventilation program at Loma Linda University Children's Hospital. Twenty-three have tracheostomies with 22 using ventilators for varying periods during the day; 36 use noninvasive ventilation, either bi-level or CPAP via mask, predominantly during sleep.

The most common mask is the Simplicity® mask (Respironics), but on some of the bigger children we use the Mirage® full face mask (ResMed). There is a definite need for smaller masks and for appropriate sized headgear for children. The home care res-

piratory therapists alter the straps to make them work for the children. Although the staff alters the headgear to fit the smaller heads, we do not currently make any kind of custom mask.

The most common ventilator, and definitely the workhorse, is the LP10 (Puritan Bennett), and the PLV®-100 (Respironics). We may soon use the LTV900™ or LTV950™ (Pulmonetic Systems).

Catherine Lockwood, RN

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We have 22 children using NPPV with a variety of masks, mostly from Respironics and ResMed. The only custom masks we make are for infants needing CPAP. The ventilators we use are the PLV®-100 and BiPAP® (Respironics), and Sullivan VPAP® (ResMed). ■

MASK AND VENTILATOR SOURCES

Ackrad Laboratories, Inc.
Cranford, New Jersey
800-684-4252
www.ackrad.com
INCA® infant nasal CPAP

AirTec Beatmungshilfen
Mülheim an der Ruhr
Germany
+49 0208 74039802
www.beatmungshilfen.de
Custom masks

B & D Electromedical
Warwickshire, England
+44 1789 293460
+44 1789 262470 fax
Nippaed

Breas Medical AB
Molnlycke, Sweden
+46 31 868800
www.breas.com
PV 101, 102, 401

Hamilton Medical, Inc.
Reno, Nevada
800-426-6331
www.hamilton-medical.ch
Arabella® infant nasal CPAP

Hans Rudolph, Inc.
Kansas City, Missouri
800-456-6695
www.rudolphkc.com
Commercial masks

Porta-Lung, Inc.
(distributed through Respironics)
Denver, Colorado
303-288-7575
www.porta-lung.com

Pulmonetic Systems, Inc.
Colton, California
800-754-1914
www.pulmonetic.com
LTV™ 900, 950, 1000

Puritan Bennett
Pleasanton, California
800-635-5267
www.mallinckrodt.com
LP10, nasal pillows

ResMed Corp.
Poway, California
800-424-0737
www.resmed.com
Sullivan VPAP® II,
commercial masks

Respironics, Inc.
Pittsburgh, Pennsylvania
800-345-6443
www.respironics.com
BiPAP® S/T, Synchrony, Vision;
NEV-100; Quantum® PSV; PLV®
100; and commercial masks

Saime, S.A.
Savigny-le-Temple, France
+33 1 64 19 11 11
+33 1 64 41 81 30 fax
Helia

David Jayne Goes to Washington: HR 1490 Is Introduced

David Jayne, ventilator user due to ALS and founder of the National Coalition to Amend the Homebound Restriction for Americans with Significant Illness (NCAHB) (see *IVUN News*, Spring 2001), traveled to Washington, DC, in May 2001. He met with congressional leaders for a briefing during the ALS Leadership Conference. Rep. Ed Markey (D-Massachusetts) introduced HR 1490, known as the Homebound Clarification Act of 2001. Jayne attracted CNN which resulted in broad television coverage of his advocacy and increased awareness and publicity for the bill.

Jayne and the Coalition also met with Senator Jim Jeffords (I-Vermont) and his staff. Senator Jeffords introduced the Senate version of the Homebound Clarification Act in 2000 and is considering reintroducing it again this year.

On the journey home, Jayne encountered former Senator Robert Dole who signed on as honorary chairman of NCAHB.

A copy of the speech Jayne presented at the congressional briefing can be read online <http://amendhomeboundpolicy.homestead.com/speech.html>.

If you have not signed the online petition, please do so (www.petitiononline.com/abolish1/petition.html). ■

MRI-Compatible Ventilator

If you are a ventilator user and have received a physician's order for an MRI, you should be able to take the test and to use your ventilator at the same time. Due to the strong magnetic pull, no metal of any kind can be in the same room as the MRI, so the ventilator must be outside of the MRI room. A common-sense solution is simply to lengthen the hose/circuitry on the ventilator and keep it outside of the MRI site.

There are two alternatives to using your own ventilator:

1. The RespirTech PRO™, which is a small, disposable, one-time ventilator from VORTRAN Medical Technology 1, Inc. (800-434-4034; www.vortran.com/respirtech-pro.html).
2. Bio-Med Devices' MRI-Compatible IC-2A and MVP-10 which are small transport ventilators (800-224-6633; www.biomeddevices.com). ■

Thanks to ventilator user Lisa Scholtz for bringing this to our attention.

Post-Polio, Swallowing, and Cough

Chest, the journal of the American College of Chest Physicians, recently published an excellent article, "Weakness, daytime somnolence, cough, and respiratory distress in a 77-year-old man with a history of childhood polio" (*Chest* 2001; 120: 659-661).

The authors are Ahmed Mahgoub, MB, ChB, MS; Rubin Cohen, MD, FCCP; and Leonard J. Rossoff, MD, Division of Pulmonary and Critical Care Medicine, Long Island Jewish Medical Center, New Hyde Park, New York.

They examine the case and explain their diagnosis of post-poliomyelitis syndrome with recurrent aspiration pneumonia secondary to dysphagia.

A majority of people with post-polio syndrome may have bulbar involvement and swallowing difficulties, as videofluoroscopic studies have shown, although about half are asymptomatic.

This "silent laryngeal penetration" may delay discovery of the role of dysphagia and aspiration in lower respiratory tract infections.

In this case, aspiration and dysphagia, resulting in ineffective cough, is believed to be the cause of the recurrent respiratory infections.

Treatment involved a special diet and evaluation and recommendations by a speech pathologist. ■

Risks

Rick Santina (rick_santina@hotmail.com)

Barbara Waxman Fiduccia died in May 2001. Because of spinal muscular atrophy, she used noninvasive ventilation for more than 10 years, and then chose to undergo a tracheostomy last year. She was widely respected as a disability rights advocate and as an educator teaching people with disabilities about sexuality and reproductive rights. Her work led her into many other endeavors including advocacy to prevent violence against people with disabilities, and studies of genetic research, cloning, stem-cell research, and eugenics. She was an amazing force in the community and a great friend.

Assistive medical technology is a double-edged sword. It enables people to live enhanced lives and, in many cases, allows people who would have been placed in institutions to live "on the outside." However, the other edge of the sword is that it requires due diligence on the part of the person who utilizes that technology and who is ultimately responsible for its use and maintenance.

Barbara would not have wanted her death used as a means to attack assistive technology. She understood very well that a consequence of not taking responsibility for the equipment individuals used might be that these individuals would be placed somewhere where responsibility would be assumed by someone else – for their own good, of course.

Barbara died because a part failed. The same part had failed three weeks earlier while she was visiting her husband Dan at Stanford Hospital. Thank God she was at the hospital, the same hospital she had left as a patient just weeks before. Thank God that one of the respiratory therapists who worked with her during her stay was there that day. The ER staff and respiratory therapist were able to save her.

Did the experience scare her? Yes, it did. Did she curl up in a ball and commit herself to an institution so they could take care of her? Absolutely not. Did she think about getting a different part to replace the one that failed? Yes, she was aware of the problem and was looking into another solution. So what happened?

Her husband died suddenly and her focus changed. She took her mind off of her equipment; the rest of us did, too. In the cyclone of events around her husband's death, that little piece of plastic slipped from our minds. It was a fatal slip.

When someone like Barbara dies, we look for reasons and try to place blame. We look for reasons and meaning and lessons to learn. Do we blame the manufacturer? Do we blame the caregiver? Do we blame the individual? Do we blame her friends who should have made sure the details did not slip her mind? Whom should we target? Who killed Barbara? Nobody. Her death was an accident.

Assistive technology is a tool. Sometimes we forget that wheelchairs, ventilators, scooters, and prostheses are tools. We have made the tool as

comfortable and transparent as possible, but it is still a tool.

The lesson is: respect your equipment, never take it for granted, but don't fear it. Remember that the same technology that failed Barbara one night had also enabled her to live an amazing life for thousands of nights before. We would not have been touched so deeply by her death if she had not lived such an amazing life. She showed us the best side of humanity and technology, and she made it look easy and sexy. She would not have had that impact if she had been stuck in some hole where she would have been "safe, comfortable, and looked after."

Barbara's death is a reminder that freedom is never free. Barbara would never have traded her freedom – and the risks and responsibilities that came with it – for the relative safety of a sterile institution. She would not have wanted anyone else to either. ■

CILB Conference Videos Available

Videotapes of the sessions during "Ventilation and Beyond – A Meeting of Minds," held in May 2001 in Toronto, are available from CILB (Citizens for Independence in Living and Breathing).

For an order form, contact CILB, 55 Greencroft Court, Kitchener, Ontario N2N 3H6, Canada; cilb@idirect.com.

GINI Research Fund Call for Proposals. The GINI Research Fund awarded its first grant in 2000 to a Toronto-based team to study "Ventilator User Perspectives on the Important Elements of Health-Related Quality of Life." The study data is expected by the end of 2001.

The next grant will be awarded in 2003, with proposals due and reviewed in 2002. For information on applying for the grant, contact Joan Headley, GINI (314-534-0475, 314-534-5070 fax, gini_intl@msn.com).

HCFA Changes Name. The Health Care Financing Administration (HCFA), the agency that administers Medicare and Medicaid, is now the Centers for Medicare and Medicaid Services (CMS). The new name, announced by Health and Human Services

Secretary Tommy G. Thompson in June 2001, reflects an increased emphasis on responsiveness to beneficiaries and providers, and on improving the quality of care. The three new centers are the Center for Beneficiary Choices, the Center for Medicare Management, and the Center for Medicaid and State Operations (www.hhs.gov). The administrator is Thomas A. Scully.

IVUN Resource Directory Online. The 2001/2002 edition of the *IVUN Resource Directory* will be online in October (www.postpolio.org/ivun). Printed copies of the *Directory* are available for \$5 postpaid (\$6 Canada & Mexico; \$7 overseas air) from GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108-2915 (314-534-0475; 314-534-5070 fax; gini_intl@msn.com).

Travel Websites. Spurred on by the Americans with Disabilities Act of 1990 and the Air Carrier Access Act of 1986, the number of passengers with disabilities is increasing.

One of the best travel websites for people with disabilities is Access-able Travel Service (www.access-able.com). Valuable travel tips can be found in the "frequently asked questions" (FAQs) section. Access-able also offers a monthly e-mail newsletter.

Other sites:

The Society for Accessible Travel and Hospitality (SATH)
www.sath.org

Mobility International USA
www.miusa.org

FAA and airline travel for people with disabilities
www.faa.gov/acr/dat.htm

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