Winter 2001 Vol. 15, No. 4

Home Mechanical Ventilation: A Brazilian Experience

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Brazil is South America's largest country with a population of approximately 169 million concentrated in the southeast. The public health care system is experiencing a lack of governmental financial resources and hospital beds, as well as differences in the level of social development among cities, resulting in insufficient care for the majority of the population.

The market has responded with tremendous growth in the private health care sector; private insurance companies, medical cooperatives, and self-administered groups are responsible for 24.5% of total health care assistance. Unfortunately, privatized care is limited to the largest cities and people fortunate enough to receive those benefits.

Even this privileged sector experiences shortages in beds and services for their clients. Here home care enters as a viable alternative. The fastest growing part in the country's health care system currently has more than 120 home care companies serving approximately 5,000 patients with 99% of their home care costs paid by the private sector.

The newness of home care in Brazil is followed by an even more recent development – home mechanical ventilation (HMV). Currently, there are 200 HMV patients in the country and the two largest home care companies, Home Doctor and Med Lar,

care for 53 of these patients (66% adults, 33% children). HMV is used invasively by 87% of these patients and non-invasively by 13%. Neuromuscular and pulmonary diseases are the most widely diagnosed.



Philippe

Within the home care companies, an interdisciplinary approach is taken. The doctor initiates the order, after which social service agents, physiotherapists (the respiratory therapy profession is represented by specialized physiotherapists), and nurses assess the home setting and recommend the necessary modifications.

In the beginning, the process was not so easy. Appropriate home ventilators were not available, and many adaptations to the existing ones were needed. The biggest challenge was in finding one suitable for children weighing less than ten kilos.

High-pressure gas sources were required, making cylinder networks of air and oxygen necessary in home settings. Recently, the LTV™ series from Pulmonetic Systems, Inc. and Newport Medical Instruments E 150 eliminate this need, yet the high cost still restricts patient access.

Other ventilators such as the PLV®-100 and three BiPAP® models from Respironics are commonly used. Support in the home is provided by weekly doctor and registered nurse visits, daily physiotherapeutic treatment, 24-hour auxiliary nursing care (other caregivers are not legally eligible to provide this care, such as family), monthly dietitian visits, speech therapy, and psychological treatment as needed.

The costs involved in this process are high, but still cheaper than using hospitalization. Proof of the cost reduction is evident in the growing number of private insurance companies that have widely accepted HMV.

The same solution for the public sector with its budget difficulties, lack of beds, and difference in social development would save hospital space for those in need of treatment there. The government is currently exploring this option in order to ration and optimize resources, and we hope soon we will see new laws and spending measures for the best of Brazil's entire population.

Fresh Air Camp

Kyle had never been away from his parents before, but summer camp promised to be a week of firsts for the 8-year-old. By the time it was over, he had gone fishing for the first time, attended his first dance, starred in the talent show, rode a horse, listened to ghost stories around the campfire, and made more new friends than he could remember.

It is a common story told by millions of summer campers over the years. But what sets Kyle apart is the fact that he has severe neuromuscular weakness, cannot hold up his head or swallow, and uses a ventilator fulltime.

Kyle and 11 other children (ages 5 to 18) with ventilators got their first taste of the summer camping experience the week of June 10-15, 2001, at the inaugural Fresh Air Camp in Moreland Hills, Ohio. The residential camp was funded by grants and donations and was offered free of charge to the campers and their families.

The Fresh Air Camp is one of several ventilator camps across the United States. It was inspired by the Trail's Edge Camp held annually in neighboring Michigan. In fact, staff members from the Michigan camp provided plenty of advice to their Ohio counterparts on the complicated business of organizing, staffing, and operating a camp for ventilator-assisted children.

The Fresh Air Camp was staffed around the clock by volunteer physicians, nurses, respiratory therapists, and other personnel from the Cleveland Clinic Children's Hospital, the Cleveland Clinic Children's Hospital for Rehabilitation, Children's Hospital Medical Center of Akron, MetroHealth Medical Center, and Rainbow Babies and Children's Hospital.

A registered nurse, a physical therapist, and a camp "buddy" attended to each child's medical needs. A physician was on site at all times.

In addition to the 150-person volunteer staff, the camp also benefited from donations of spare equipment from home health care companies. Generators were positioned around the campground in case of an electrical emergency, and extra ventilators were available in the event a camper's ventilator failed.

The camp derived its name from the Cleveland Clinic Children's Hospital for Rehabilitation, which was known early in its 112-year existence as the "Children's Fresh Air Camp."

Fresh Air Camp's second session is scheduled for June 9-14, 2002, at the same location. For more information, contact Kathy Whitford, CPNP (216-721-7159, www.freshaircamp.org).

CALENDAR 2002

APRIL 1-7. VACC Camp.

Miami, Florida. Contact Bela Florentin, VACC, 3200 SW 60th Court, Suite 203, Miami, FL (Florida) 33155 (305-662-8222, 305-663-8417 fax, bela.florentin@mch.com, www.vacccamp.com).

Ventilators Find Good Home

The IVUN office received a message this fall that several used ventilators were available. Nicole Jefferson, daughter of respiratory polio survivor Jenniss Jefferson who died in July, wanted to donate her mother's ventilators to anyone who might need them. These included two LPs, one PLV®-100, and an old Thompson.

Just days later, in one of those serendipitous moments, the Children's Wishing Star, an organization working in El Salvador, requested a home ventilator for a child with SMA III. The match was made, thanks to IVUN staffer Carol Cox, and the ventilators were promptly on their way to El Salvador.

Children's Wishing Star was founded nearly 6 years ago by Pat Kujawa. When Pat returned from El Salvador after pursuing the adoption of daughter Karoline, she felt a great call to do more. She and her husband Stan were able to open a home in the capitol, San Salvador, that would take the overflow of children from the only pediatric hospital in the area, The Benjamin Bloom Hospital.

The home is located right next to the hospital and cares for children from the ages of infant to 12 years old. The children come for treatment and stay under a doctor's care until they are able to return home. Some children are fighting cancer, others are abused, many are malnourished. The hospital needed a ventilator in order to discharge Omar, almost 6 years

Sleep Studies: At Home or in the Lab?

Judith R. Fischer

Problems with breathing may be noticed first during sleep. In people with neuromuscular disorders, these problems can be due to underventilation, to apnea (obstructive, central, or mixed), or to a combination of both. To establish a definitive diagnosis of obstructive sleep apnea (OSA) – the most common form – the physician usually orders a sleep study or polysomnography (PSG) in a sleep laboratory.

However, in the last several years, home sleep studies to detect OSA have become more common and may decrease the waiting period for sleep lab studies. The home study can provide the correct diagnosis in 70-80% of cases among the general population, but the level of effectiveness in diagnosing OSA in people with neuromuscular conditions has yet to be sufficiently studied.

A sleep study provides information about the quantity and quality of an individual's sleep in both REM and non-REM sleep by monitoring arousals and leg movements, the number of hypopneas and apneas (known as the apnea/hypopnea index or AHI), the kind of apnea, breathing efforts, air flow, and levels of oxygen saturation in the blood (SaO₂).

Generally, standard PSG in a sleep lab measures the different sleep stages with two EEG leads (for brain activity), two electro-oculographic leads (for eye movements), and one electromyogram lead near the chin or throat (for muscle activity). With the information gathered through these leads or channels, an individ-

ual's sleep pattern emerges. In addition, an EKG monitors heart rate, and a pulse oximeter monitors SaO₂. Some labs also monitor snoring and body position. The more channels that are used, the more data collected.

The main advantage of sleep lab testing is that a technician is always present to monitor the equipment as well as to handle a medical emergency. The main disadvantages are usually cost, long waiting period, and a strange and unfamiliar sleep environment that does not lend itself to accurately reproducing an individual's normal sleep.

A sleep study in the home is less expensive and provides a familiar sleep environment, although some people may still have difficulty sleeping with all the wires. A full PSG in the home can supply as many as 20 channels of data. A disadvantage is that, with unattended equipment, data may be lost, requiring another test, which can end up being just as expensive as a sleep lab PSG. However, even though unattended. home studies can be monitored via a modem, so that if a lead falls off, the sleep technician calls the home and asks the individual to put the lead back on. The whole night is not lost, but the disruption is not ideal either. It is important to note that the degree of severity of OSA may not be picked up with a home study, especially if the individual sleeps poorly.

In 1993, the American Sleep Disorders Association (now the American Academy of Sleep Medicine) published a guideline setting minimum standards for home studies. The home recording unit must measure at least four channels: heart rate. SaO₂. air flow, and breathing effort. (This may not provide enough data when used for people with neuromuscular disease.) Joint clinical practice guidelines on "Home Testing for the Diagnosis of Sleep-Disordered Breathing" are currently being developed by the American College of Chest Physicians (ACCP), the American Thoracic Society (ATS), and the American Academy of Sleep Medicine (AASM).

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International Ventilator Users Network

IVUN News (ISSN 1066-534X) Winter 2001 ■ Vol. 15, No. 4

IVUN News links ventilator users with each other and with health care professionals interested in mechanical ventilation and home care.

ISSUED IN MARCH, JUNE, SEPTEMBER, DECEMBER

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COORDINATED AND PUBLISHED BY
Gazette International Networking
Institute (GINI)

Annual Subscription (US dollars only)
USA: \$17

Canada, Mexico, and Overseas surface: \$22 Overseas air: \$27

To subscribe, send check made payable to "GINI" (USD) or VISA, MasterCard, or Discover credit card number, expiration date, and name on card to the above address.

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More on Oxygen Use

E.A. (Tony) Oppenheimer, MD, FACP, FCCP (eaopp@ucla.edu)

Are there circumstances when using oxygen might be appropriate for a person with respiratory muscle weakness due to neuromuscular or musculoskeletal disease? Yes, there are several situations in which using supplemental oxygen is warranted.

For people who are not using any type of ventilator

- Oxygen might be used if the individual does not want to use any type of assisted ventilation but wishes to have symptomatic relief without improving survival; this is often called palliative care.
- Supplemental oxygen is justified if the arterial carbon dioxide (CO₂) is repeatedly not elevated, indicating that there is no hypoventilation, but the oxygen saturation (SaO₂) is 88% or lower and the arterial oxygen (PaO₂) is 55 mm Hg or less. Adjusting the added oxugen to achieve oxygen saturation of 90-95% should be on the advice of one's physician. He or she may prescribe it only at night or whenever the oxugen saturation is 88% or lower. Sometimes the cause for this is difficult to identify, but can occur more often at higher altitudes, such as Denver or Mexico City, than at sea level because at altitude, atmospheric

pressure is reduced and this decreases the availability of oxygen.

For people who are using a ventilator (noninvasively or via tracheostomy) to successfully treat hypoventilation caused by respiratory muscle weakness resulting in normal arterial CO₂

- Oxygen might be needed if there is also a chronic lung or heart problem such as COPD, pulmonary fibrosis, cor pulmonale, or heart failure.
- Oxygen might be needed if there is an acute lung problem, such as pneumonia, until this resolves.
- Oxygen might be needed if one is living (or visiting) at altitude in cities such as Denver or Mexico City. If the ventilator is adjusted properly so the arterial CO₂ is normal, but the high altitude causes the oxygen saturation to drop to 88% or lower and the arterial PaO₂ is 55 mm Hg or less, then supplemental oxygen is justified - again adjusting the added oxygen to achieve an oxugen saturation of 90-95% following the advice of one's physician. A variation of this, often at altitude, might be that the night-time adjustment of the ventilator, despite all attempts.

is not optimal (perhaps due to leaks), so the physician may suggest adding supplemental oxygen rather than considering tracheostomy.

In air travel, the airplane often flies at about 30,000 feet. with the cabin pressure adjusted to between 5,000 to 8,000 feet. This is equivalent to being at high altitude. The arterial oxygen would drop by at least 16 mm Hg, compared to the sea level value. A person who usually only uses night-time ventilation may need supplemental oxygen during air travel. A physician would need to advise, arrange this, and determine the oxygen flow (usually available either with 2 or 4 liters per minute). Some people need to be sure a small portable oxygen tank will be available in order to leave one's seat and use the toilet.

The general guideline is true — oxygen is not the right treatment for hypoventilation due to respiratory muscle weakness. In fact, using oxygen rather than assisted ventilation can result in serious complications. However, in the situations described above, using oxygen can be quite reasonable and important. The individual needs to discuss this with their physician to get the best advice.

Ventilators Find Good Home CONTINUED FROM PAGE 2

old, who had been living in the hospital for two years.

The gift of the ventilators is a gesture befitting Jenniss Jefferson's life. As a full-time ventilator user and quadriplegic due to polio, Jenniss worked her way through college to obtain bachelor's degrees in both psychology and history. She worked as an advocate for the disabled in Sonoma County, California, and was successful in obtaining more than 50 generators from the State which were donated to

other disabled people who were dependent upon electricity to power their ventilators. ■

For more information on Children's Wishing Star, contact Pat Kujawa, 320 Pheasant Run Place. Findlay, OH (Ohio) 45840. During the recent annual meeting of the ACCP, Nancy Collop, MD, and David Hudgel, MD, two sleep and breathing experts, discussed the pros and cons of home sleep studies. They concluded:

- home sleep studies should not be considered in isolation, but need to relate to clinical and objective variables;
- the sensitivity and specificity of findings differ with the equipment used for home sleep studies and the population studied;
- combining quality and cost may make sleep lab studies less expensive in the long run;
- big business may take over if home studies are approved by insurance carriers, and, although many HMOs have been authorizing unattended sleep studies, there is no information on outcomes.

The appropriate study for an individual with a neuromuscular disorder may depend on how much data the physician needs and what symptoms the individual is experiencing. If there is a classic presentation of OSA – snoring, daytime sleepiness, high blood pressure, and observed apneas during sleep – then the individual can be studied either at home or in a sleep lab.

People with mild sleep apnea or upper airway resistance syndrome (in which there are arousals during sleep related to inspiratory effort against a narrowed airway, but no clear-cut OSA) would be **New Interfaces and Equipment**

LTV800[™] is the latest laptop ventilator available from Pulmonetic Systems and is specifically for the individual who needs only volume ventilation. The LTV800[™] is the least expensive model. Contact your home health care dealer or Pulmonetic Systems (800-754-1914, www.pulmonetic.com).

Aclaim nasal mask, new from Fisher & Paykel Healthcare, combines foam with silicone to provide a comfortable fit. GLIDER headgear enables the mask user to change position, while the mask stays in place. The fit is aided by an adjustable T-piece. The Aclaim is two sizes in one, achieved with a simple change to one part of the mask. Contact your home health care dealer or Fisher & Paykel (800-446-3908, www.fphcare.com).

Mirage® Full Face Mask Series 2 from ResMed offers a better seal and stability through a new mask frame and cushion. The cushion is shaped around the nose so that only it comes into contact with the bridge of the nose. This new mask series also comes with new headgear featuring Breath-o-prene™ material. Contact your home health care dealer or ResMed (800-424-0737, www.resmed.com).

BiPAP[®]/**pro with Bi-Flex**[™] is new from Respironics for those with obstructive sleep apnea who do not need a backup rate. Contact your home health care dealer or Respironics (800-345-6443, www.respironics.com).

RoEzIt®, a petroleum-free moisturizer, can be used in nasal passages and on the face when skin becomes dry due to mask usage. RoEzIt® costs about \$7.95 per tube and is available from LouSal Enterprises, Inc. (866-323-4567, www.roezit.com). ■

better evaluated in a sleep lab. Insurance coverage also plays a role in determining whether a home study or a sleep lab is selected. Medicare does not cover home sleep studies.

Special thanks to Nancy Collop, MD, and to The American Sleep Apnea Association, 1424 K Street NW, Ste 302, Washington DC 20005 (202-293-3650, 202-293-3656 fax, www.sleepapnea.org).

The American Academy of Sleep Medicine, which accredits sleep disorder facilities, differentiates between those that are full-service sleep disorders centers and those that are specialty laboratories for sleep-related breathing disorders. The centers may see any individual with a sleep disorder, but the laboratories treat only breathing-related disorders. The AASM provides a listing of accredited sleep labs: www.aasmnet.org/listing.htm.

Dr. Alba Honored

Augusta S. Alba, MD, received the Margaret Pfrommer Memorial Lecture Award from the American College of Chest Physicians at their annual meeting in Philadelphia in November 2001.

Dr. Alba is well known to *IVUN News* readers for her commitment and lifelong dedication to people living at home with ventilators. She is a most deserving recipient of this award, and *IVUN* congratulates her.

Potpourri

Homebound Clarification Act. HR 1490, introduced by Congressmen Ed Markey (D-Connecticut) and Chris Smith (D-New Jersey), on behalf of David Jayne's National Coalition to Amend the Medicare Homebound Restriction (NCAHB), needs more congressional sponsors.

IVUN News readers are asked to contact their congresspeople to urge them to co-sponsor the bill. Sample letters are posted on the NCAHB Web site: www.amendhomeboundpolicy. homestead.com.

*** * ***

Flying with the LTV. Barbara Rogers, ventilator user and frequent flier, advises that the LTV™ series from Pulmonetic Systems, Inc., has been approved by the FAA for use during take-off and landing. These ventilators received certification that they do NOT interfere with radio and other transmissions. Unfortunately, most airlines are unaware of the actual FAA regulations.

For more information, contact Barbara: breethezy@aol.com.

*** * ***

GINI Research Fund Call for Proposals. The GINI Research Fund's next grant will be awarded in 2003, with proposals due and reviewed by March 1, 2002.

For information on applying for the grant, contact Joan Headley, GINI (314-534-0475, 314-534-5070 fax, gini_intl@msn.com, www.post-polio.org/gini/grf-1.html).

*** * ***

IVUN Resource Directory
Online. The latest edition of
the IVUN Resource Directory
2001/2002 is now available
online: www.post-polio.org/
ivun/d.html.

Printed copies of the *Directory* are available for \$5 postpaid (\$6 Canada & Mexico, overseas surface; \$7 overseas air) from GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915 USA (314-534-0475, 314-534-5070 fax, gini_intl@msn.com).

www.DoctorBach.com is the Web site to hit to find out about noninvasive ventilation as advo-

cated by John R. Bach, MD.

The Center for Noninvasive Mechanical Ventilation Alternatives and Pulmonary Rehabilitation, created by Bach in 1992, is initiating an annual course—"The Evaluation and Management of Patients with Neuromuscular Disease"—scheduled for May 2002.

Treatment of Pulmonary
Disease Following Cervical
Spinal Cord Injury (AHRQ
Publication No. 01-E014, June
2001) is the full evidence report
prepared by the Agency for
Healthcare Research and
Quality by the Duke Evidencebased Practice Center.

Copies may be obtained free of charge from the AHRQ Publications Clearinghouse (800-358-9295) or read online: www.ahrq.gov/clinic/epcix.htm.

Pearson's Respiratory Outreach Program Moves Into Community

Irene Hanley, RRT

The Provincial Respiratory Outreach Program (PROP) which has been located at George Pearson Center in Vancouver, British Columbia, since the 1960s now will be located and operated within a community setting. After discussions over the past three years about the strengths and weaknesses of the program, a committee formed last year by the Vancouver/ Richmond Health Board, including clients, stakeholders, and community groups, examined how to improve the existing program.

As a result of the committee's recommendations, the PROP, effective November 1, 2001, will begin transferring from the Pearson Center to the British Columbia Paraplegic Association (BCPA) in conjunction with Technology for Independent Living (TIL). The transfer will take place over a number of months to ensure a smooth and concise transition. The new PROP will be operated by the BCPA, and I will continue to be the Respiratory Coordinator. People will still be able to receive a ventilator and supplies at no cost, but the addition of fully qualified BCPA, TIL technical staff, and more registered respiratory therapy staff will enable the PROP to be very client-specific.

PROP's new address is British Columbia Paraplegic Association, 780 SW Marine Drive, Vancouver, BC (British Columbia), Canada V6P 5Y7 (866-326-1245 toll-free in BC, 604-326-1246, 604-326-1250 fax, prop@bcpara.org).

Reeve Paralysis Resource Center

The Christopher and Dana Reeve Paralysis Resource Center (PRC) recently received \$2 million in federal funding from the Health and Human Services Department for the creation of a new central resource for people living with paralysis, their families, and their caregivers. It will be the most comprehensive and accessible resource available to people living with paralysis and will be dedicated to improving their quality of life.

The PRC facility, to be housed in Short Hills, New Jersey, will provide a staff of specialists who will coordinate a comprehensive library, Web site, educational materials, referral services, and self-help information. The first phase of the multimillion-dollar PRC initiative will be the launch of a national interactive survey, conducted online and by mail. The survey is posted on www.paralysis.org.

"One of the most disabling aspects of paralysis is the lack of resources and support necessary to get back into a world that has completely changed for the paralyzed individual – both economically and socially," said Reeve. "When somebody is first injured or as a disease progresses into paralysis, people don't know where to turn. We will provide that support and information to people."

IVUN has urged PRC to include information and resources for assisted breathing and home mechanical ventilation as a vital part of the program.

Dear Ventilator Users and Caregivers,

I am writing a book, entitled Stories of Ventilator Users ... You're Not the Only One, to help people who use ventilators, from new users to long-time users, learn from each other's experiences. As

a ventilator user myself, I believe we all have learned a lot of lessons that can be useful to others – either great ideas or helpful ways to avoid unpleasant experiences.

Topics for chapters include types of ventilators, medical conditions requiring assisted ventilation, nursing care, complications, nutrition, family support, physical rehabilitation, psychological



support, dealing with insurance companies, and assistive technology.

I have assembled a list of questions to provoke your thoughts, and I hope you will answer the ones that you can based upon your own experiences. The time you spend in responding may be nothing compared to the time it saves other ventilator users in the future.

Answers to the questions will be used in the following way in the book: "a 25-year-old male with Duchenne muscular dystrophy suggests ..."; "a 50-year-old female with post-polio has experienced ..."; and "a 37-year-old male with C-3 quadriplegia suggests that ... works best." I may also use your answer to a question as a direct quote. I want to be clear that this book will not be a just collection of your stories, but a thoughtful blending of all of your ideas.

The proceeds of the book will benefit International Ventilator Users Network (IVUN), so that they will be able to distribute more of their quarterly newsletters free of charge.

The questionnaire is online at the IVUN Web site: www.post-polio.org/ivun. It is also available by e-mailing me (ventusers@ yahoo.com) or writing to P.O. Box 771, Arlington Heights, IL (Illinois) 60006-0771.

Bryan Pratt

ED. NOTE: Bryan has used a ventilator (LP10) fulltime since December 30, 1997. He is 28 years old and has had facioscapulohumeral muscular dystrophy since birth. He received a Bachelor of Science degree in Materials Science and Engineering from the University of Illinois. Bryan's writing skills were honed as volunteer editor of the university's annual magazine for the disabled student organization. His autobiography, *Look Beyond This Cover*, was just released.

Aging With a Ventilator: Independence or Security?

Several ventilator users in the United States who are at retirement age or who no longer want to deal with owning and maintaining a home face a dilemma about where to move. Many retirement communities offer progressive levels of care ranging from an individual apartment to assisted living to a nursing home.

Jerry Grady (jsgrady@aol.com), who has used a ventilator during the night for several years, wanted to sign up for an apartment in a such a retirement community, but he was told by the administrator that if and when he needed to use the ventilator fulltime (perhaps mistakenly assuming he would at that point need to live in the nursing home wing and require extra care), he would not be allowed to stay.

Finding a nursing home to care for a ventilator user is another problem. Previously, IVUN tried to locate nursing homes that would admit ventilator users, but found that they do not abound in great numbers.

The relative lack may be understandable but not excusable when one considers that nursing homes receive inadequate reimbursement for respiratory therapy, they perceive increased nursing time and cost for patients who use ventilators, and there is fear among the staff of equipment that is "life support."

A great deal of education is necessary to correct misperceptions and overcome fear, as well as lobbying for increased reimbursement for respiratory therapy. Dick Wieler (RLWieler@aol.com) writes. "As I drift even farther away from my working days, I begin to question the quality of my living conditions. Even with the assistance of a home health care agency, the quality of the help is spotty and the constant turnover frustrating. I'm beginning to feel the need for security more than the need for independence. As I explore the avenues of assisted or skilled care facilities. I find even more questions rather than answers, and I am curious about the findings of others in my predicament."

IVUN welcomes additional stories, advice, solutions, etc. Please send them to IVUN, 4207 Lindell Blvd., #110, Saint Louis, MO (Missouri) 63108 (gini_intl@msn.com).

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PURITAN TT3NN38



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