

POST-POLIO HEALTH

FORMERLY POLIO NETWORK NEWS

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GINI Is Now Post-Polio Health International

The mission of Post-Polio Health International

To enhance the lives and independence of polio survivors and home mechanical ventilator users by promoting education, networking, and advocacy among these individuals and healthcare providers.

Gazette International Networking Institute (GINI) has changed its name to Post-Polio Health International to reflect a more focused scope of services and broader constituency, and has developed a new membership structure to strengthen the organization's advocacy role.

The new name, Post-Polio Health International, is meant to project the broadest meaning of "health," encompassing the physical, emotional, social, psychological, and spiritual aspects of individuals' lives. The new name also reaffirms an ongoing interest in international issues.

"We knew that GINI meant only 'post-polio' or 'home ventilator use' to those who knew our past. We decided to focus on the future – knowing that our founder, Gini Laurie, would have agreed," said Frederick M. Maynard, MD, board president. "And in Gini's tradition, board and staff have worked hard to roll out the new plans."

While the majority of the people it serves are polio survivors, Post-Polio Health International will continue to respond to the needs of all ventilator users through its affiliate, International Ventilator Users Network. Historically, the first ventilator users were polio survivors who had used iron lungs. Now, a growing number of people with a variety of conditions use home mechanical ventilation.

"We decided to focus on the future – knowing that our founder, Gini Laurie, would have agreed."

Frederick M. Maynard, MD
Board President

Needs Assessment Drives Planning Process, Changes

"Well-managed organizations periodically evaluate themselves to make sure they are fulfilling their mission," Maynard said. "The board undertook the strategic planning process to determine how our organization could more effectively meet the needs of the people we serve." Taken into consideration were independent survey feedback from subscribers and their families, website visitors, sponsors, donors, and health professionals.

Respondents overwhelmingly complimented the quality of the newsletters, and they will expand – beginning immediately in the case of the newsletter for ventilator users. The newsletters have been renamed *Post-Polio Health* (replacing *Polio Network News*) and *Ventilator-Assisted Living* (formerly *IVUN News*). Future issues of both will feature new formats and more news. *Rehabilitation Gazette* was discontinued, and pertinent cross-disability information will be incorporated into both of the newsletters.

Surveys also revealed that support group leaders and organizations with similar missions value Post-Polio Health International's willingness to provide assistance


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OUR NAMES THROUGH THE YEARS

- 1960** International Iron Lung Polio Assistance, Inc.
- 1964** Iron Lung Polios and Multiplegics, Inc.
- 1970** Rehabilitation Gazette, Inc.
- 1983** Gazette International Networking Institute, Inc.
- 1985** Doing business as International Polio Network
- 1987** Doing business as International Ventilator Users Network
- 2003** Post-Polio Health International including International Ventilator Users Network

and depend on our storehouse of knowledge and reserve of interconnected people. Outreach programs under development will identify additional organizations and individuals with compatible goals and philosophies to create influential relationships to further the mission.

The new membership structure is designed to strengthen Post-Polio Health International's ability to advocate for its constituents. Current newsletter subscribers are automatically members of Post-Polio Health International and/or its affiliate International Ventilator Users Network. A membership form on page 11 describes the membership levels and offers current subscribers an opportunity to expand their support.

"We encourage our members to pass the membership form on to others – polio survivors, family members and friends, and health professionals – and ask them to join us," said Maynard. "By becoming members, they, too, can support our causes and contribute to the legacy of a truly unique organization." 

The Board thanks the Genskow family who honored their husband and father, Jack Genskow, a former Board member, polio survivor, ventilator user, and disability activist. Their donation, in recognition of his long-standing work with Gini Laurie and the organization, helped fund this process.

From the Editor ...

Our inaugural issue of *Post-Polio Health* includes "A Statement about Exercise for Survivors of Polio" (pages 4-6). Motivated by messages from people who have developed an exercise program and report that they definitely feel better, I facilitated this process. Typically they add, "but don't tell anyone, because polio survivors shouldn't exercise" or "I don't want to raise other peoples' hope."

While some people have discouraged exercise because they believe "polio survivors will just overdo it," I believe we can be trusted to make intelligent decisions about our health when given good information.

I intend to continue our focus on health – in the broadest sense – to personally empower you. We ask you to encourage others to join Post-Polio Health International to strengthen the power of the group.



Joan L. Headley, Executive Director
Post-Polio Health International

Neurontin has been touted on the Internet as "the best medication for post-polio syndrome," which is an overstatement, if not an erroneous one. Dr. Perlman examines the drug, aka gabapentin.

Gabapentin AKA Neurontin

Susan L. Perlman, MD, Associate Clinical Professor of Neurology,
UCLA Medical Center, Los Angeles, California (sperlman@ucla.edu)

Gabapentin (brand name Neurontin) appears to be the "new Prozac." It was on the 2001 list of the top 50 prescription medications dispensed in pharmacies. Since its release in 1993 for the treatment of partial seizures in children and adults with epilepsy, gabapentin has also been studied for use in many different causes of pain (reflex sympathetic dystrophy, diabetic neuropathy, neuropathy from chemotherapy, Guillain-Barré syndrome, restless legs, and other neuropathic pain, muscle, and joint pain). Smaller studies have been done for migraines, tremors, certain muscle disorders (stiff-person syndrome), certain eye movement problems (nystagmus), manic-depressive illness (bipolar disorder), schizophrenia, substance abuse, and even for sleep maintenance problems, and perimenopausal hot flashes.

A search of the medical literature yields over 1,000 references to its uses in therapy, although the FDA has so far approved it only for epileptic seizures and, in May 2002, for post-herpetic neuralgia (shingles). A recent review of its use in neuropathic pain suggests it can be started and increased over a week or so to effective doses in the 1,800-3,600 mg per day range (lower in people with kidney disease), with excellent reduction in pain and improvement in quality of life, mood, and sleep.¹

This breadth of use of gabapentin is due in part to its mechanism of action. Calcium channels ("voltage-gated") are important in nerve cell growth, nerve cell activity levels, and nerve cell death and have been found to be altered in animal models of neuro-

pathic pain.² Gabapentin seems to help correct this.

Because of the involvement of these channels in the health of nerve cells, gabapentin was also tested for its ability to protect nerves in animals³ and in people with Lou Gehrig's disease,⁴ but was not found to be helpful.

The popularity that gabapentin has attained certainly relates to its broad effectiveness for various neurologic conditions, including pain, but also to its modest side effects. Adverse effects (commonly dizziness or imbalance, fatigue, and sleepiness) are usually mild to moderate, but occur soon after starting the drug, don't appear to get worse at higher doses, and often go away after the first month. Gabapentin doesn't interact with other medications (although it shouldn't be taken at the same time as certain antacids, like Maalox), and only rarely causes allergic reactions.

Polio survivors, experiencing pain from nerve or muscle areas, restless legs, or disturbed sleep because of these factors, might be recommended to try gabapentin by their physician, as an "off-label" use supported by the various studies reported in the medical literature. However, the common side effects of fatigue or imbalance might not be well tolerated by a post-polio person who already has problems with low daytime energy levels and declining mobility. Starting at lower doses and increasing more slowly over time might minimize these undesirable effects. ☞

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A statement about exercise for survivors of polio

Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for

many polio survivors, including those with the symptoms of post-polio syndrome.* (*References are listed on page 6.*)

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the re-sprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The premature death of some of the AHCs affected by the polio-virus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise.

There is agreement that repetitive overuse can cause damage to joints and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured, and repetitive body movement.

*Criteria for diagnosis of post-polio syndrome

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.
- Symptoms persist for at least a year.
- Exclusion of other neurologic, medical, and orthopedic problems as causes of symptoms.

Source: *Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care*. March of Dimes, 2001.

Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance, and/or to increase the capacity for physical activity.

Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy. But, some polio survivors' weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular deconditioning.

The research supports the fact that many survivors can enhance their optimal health, their range of motion, and their capacity for activity by embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities. These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

Exercise programs should be designed and supervised by physicians, physical therapists, and/or other health care professionals who are familiar with the unique pathophysiology of post-polio syndrome and the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two – four months. During this period, they will monitor an individual's pain, fatigue, and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

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When designing a program, these general principles are followed to achieve specific goals and/or maintenance levels.

- The intensity of the exercise is low to moderate.
- The progression of the exercise is slow, particularly in muscles that have not been exercised for a period of time and/or have obvious chronic weakness from acute poliomyelitis.
- Pacing is incorporated into the detailed program.
- The plan should include a rotation of exercise types, such as stretching, general (aerobic) conditioning, strengthening, endurance, or joint range of motion exercises.

Polio survivors who experience marked pain or fatigue following any exercise should hold that exercise until contacting their health professional.

Researchers and clinicians cannot make a more definite statement until additional studies on the long-term effects of exercise and the effects of exercise on function and quality of life are undertaken. ❧

continued on page 6

A statement about exercise for survivors of polio

continued from page 5

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Visit www.ncpad.org
and review
"To Reap the
Rewards of Post-
Polio Exercise"
by Sunny Roller, MA,
University of Michigan
Health System,
Ann Arbor, Michigan,
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Update on the Mouse Model Research

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Burk Jubelt, MD, Upstate Medical University, Syracuse, New York, reports that he and his colleagues will complete their scheduled laboratory work by the end of April 2003. The mice have shown degenerative nerve damage in function and in EMG studies. No evidence of active virus or viral replication has been seen. The project is also looking for evidence of immune mediated involvement. After the data is collected and analyzed, the work will be submitted to a medical journal for publication.

In the next phase of the research, the team will try different therapies such as nerve growth factors and pharmaceuticals on the mice to see if their neurological function will improve.

Visit-ability

The idea, spearheaded by Atlanta disability activist Eleanor Smith, founder of Concrete Change (www.concretechange.org), refers to basic access in all new homes – so that they are “visitable” by people with mobility problems. A no-step entrance, doorways wide enough to get through, and a bathroom big enough to get into and close the door – these are visitability’s three simple points.

There are numerous sites on the Internet that offer information. One such site is Homes for Easy Living (www.homesforeasyliving.com) or go to www.google.com and type in “universal design” or “visitability.”



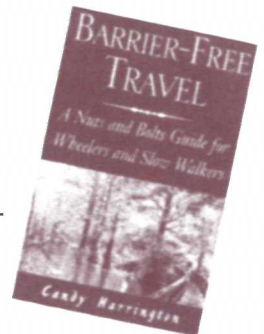
New Accessibility Symbol



The National Endowment for the Arts funded the development of 12 new disability access symbols, developed by Graphic Artists Guild, <http://gag.org/resources/das.php>. The new symbol for accessibility depicts a person leaning forward in a wheelchair with arms poised to push the wheels.

Accessible Travel Guide

Barrier-Free Travel: A Nuts & Bolts Guide for Wheelers & Slow Walkers is a new 230-page (\$18.69) travel guide written by Candy B. Harrington, editor of *Emerging Horizons Accessible Travel News*. To order, call 888-795-4274 or visit www.emerginghorizons.com/book. A sample chapter is online for your review.



Safe at Home Video

“Safe at Home: Planning for Independence Through Home Modification,” narrated by Bob Vila, is a new 23-minute video (\$19.95) full of practical solutions for adapting your home to prevent falls and to increase independence produced by the International Rehabilitation Center for Polio in Framingham, Massachusetts. To order, visit www.Bobvila.com or call 508-872-2200, ext 259.



The Navigator

Keen Mobility, Portland, Oregon, has unveiled the new Navigator crutch. Created to lessen the risk of osteoarthritis, the Navigator reduces the stress on the user’s shoulders, back, wrists, and elbows by cushioning the impact force of walking on crutches. The crutch also includes a micro-adjustable handle, a contour-padded underarm shelf, and a pivoting tip.

To find out more about the features of the crutch, please visit www.keenmobility.com or call 503-285-9090.

Thank you ...

- Justine Craig-Meyer, Assistant to the Executive Director and Membership Services Administrator, at her new desk donated by TYCO HEALTHCARE, INC., in Saint Louis. Special thanks to Board member, Rich Hokamp, and Vince Kaiman and Vanetta Cobbs at Tyco.
- A *Bibliography of Infantile Paralysis 1789-1949*, prepared under the direction of the National Foundation for Infantile Paralysis, is just one of over a dozen polio-related books and memorabilia donated to Post-Polio Health International. The collection, from the ROCKY MOUNTAIN LABORATORIES LIBRARY, Hamilton, Montana, includes the five books of *Poliomyelitis: Papers and Discussions Presented at the (First, Second, etc.) International Poliomyelitis Conference(s)*. These five meetings were held around the world between 1948 and 1960.



Improving Communication with Our Doctors

Henry D. Holland, MD, Richmond, Virginia (Henry4FDR@aol.com)

Most physicians follow the medical model, which is generally based on the scientific method. The thorough physician would get a complete history from you and possibly members of your family, perform a physical examination, try to obtain copies of previous medical records from other medical sources, and would get laboratory and other objective tests. Routine tests usually include a complete blood count, blood chemistries including electrolytes, liver enzymes, kidney screening tests, cholesterol, and others. A chest x-ray and thyroid function studies might also be included.

I think it is essential and extremely important to have a doctor who will listen to you. As a patient I think it is equally important for you to present your history of polio and post-polio syndrome symptoms in a concise manner and as objectively as possible. I recommend that you answer the physician's questions in a similar manner. If your doctor seems hurried, that is a distinct disadvantage for both you and him/her. It is a good idea to write some notes so you remember to tell the doctor about the onset of symptoms, when the symptoms seemed to progress, and what you have done that seemed to increase the symptoms or decrease the symptoms.

Most physicians will formulate a possible or differential diagnosis based on the history and physical exam even before the objective test results are known. In some cases, treatment may be started at that time. After the results of the objective tests are known, often the diagnosis can be made.

The diagnosis of post-polio syndrome is one of exclusion. The usual symptoms – weakness, fatigue, and pain – are very similar to other conditions. Therefore,

your physician must exclude these other possible disorders as an explanation for your symptoms. The most important initial factor is to make sure that your physician knows of the history of polio in your life.

My initial diagnosis in 1991 was a self-diagnosis. A neurologist and a pulmonary doctor did not think that I had post-polio syndrome, but I am not sure that they knew much about it. Fortunately my primary care (internal medicine) doctor was willing to listen to what I had to say. He was also willing to read the articles that I brought him. Admittedly, I had an advantage because, as a physician, my opinions and observations were not immediately dismissed.

As a patient, you can become frustrated early on in the diagnostic process. Hopefully your physician will be honest and not defensive and will admit if he/she knows little about the disorder. This is likely a good sign that the physician is willing to learn. If you can afford it, give your doctor either Managing Post-Polio, A Guide to Living Well with Post-Polio Syndrome (1998) by Lauro Halstead, MD (www.nrhrehab.org) or Post-Polio Syndrome: A Guide for Polio Survivors and Their Families (2000) by Julie Silver, MD, now in paperback (www.polioclinic.org). A gesture of this type can be mutually beneficial, but I would not recommend presenting any literature with a know-it-all attitude or to a doctor with a similar attitude. A little humility is good for both the doctor and the patient.

I often hear that polio is not taught any more in medical schools. I think this is an inaccurate perception. Infectious diseases, including polio, are taught in accredited medical schools despite the possibility that an American physician may never see an actual case. I have never seen a case of leprosy, bubonic

Why am I qualified to offer these suggestions? I have had the experience of being a patient many times in my life. I have used a ventilator since I had a permanent tracheostomy in 1970. This treatment resulted from the damage initially caused by polio in 1950. I have an intensified interest in post-polio syndrome because I have experienced its effects since about 1990.

I have been a physician since 1966, and my specialty is psychiatry. I am currently a clinical professor at the School of Medicine of Virginia Commonwealth University (formerly the Medical College of Virginia), and each year I instruct second year medical students in the technique of interviewing patients.

plague, elephantiasis, or yellow fever. However, I studied and was quizzed on all of these diseases.

Post-Polio Syndrome is probably taught less because this disorder is a "syndrome." A syndrome is a group of symptoms that collectively indicate or characterize a disease, a psychological disorder, or another abnormal condition. The causes of some syndromes are known and others are not known. When the cause of a syndrome is not clearly known, the teaching emphasis would be on recognition. As treatment may vary or change, a precise treatment plan may be suggested but with reservation. This is the case with post-polio syndrome. For example, how much exercise is enough or how much exercise is too much? The treatment of post-polio syndrome is more individualized and less empirical than known disease processes.

The average physician may never have a case of post-polio syndrome cross his/her office threshold. If a case does, that physician may focus on other causes before considering the diagnosis, assuming that he/she knows about post-polio syndrome and assuming you told him/her your polio history.

Communicate honestly about the severity of your symptoms. Many polio survivors minimize the severity and dysfunction of their symptoms. Don't hesitate to tell your story with complete disclosure of how bad you are feeling or hurting. It is important for you to communicate with clarity and emphasis about what has changed and what you are experiencing. You could simply complain of fatigue, pain, and weakness, but if you explain how the fatigue, etc., is limiting, then your doctor will begin to understand. For example, if you report that walking up a flight of steps is no longer possible without resting or extreme effort, you are more objective

in your description than simply reporting fatigue. You, as a polio survivor, understand what you are experiencing. If the doctor has a genuine ability to empathize, he/she may also be able to understand. However, the doctor may worry about missing something that is more treatable than post-polio syndrome, such as a malignancy, multiple sclerosis and other CNS diseases, HIV, or any other disease that might present with a complaint of fatigue, pain, or weakness.

The successful doctor/patient relationship depends in part on a feeling of comfort between the two personalities involved. The patient wants help with a problem and trusts the doctor to use his/her expertise in solving the problem. The doctor's goal is to diagnose correctly the patient's problem and initiate the appropriate treatment promptly.

This process will be more rewarding if the doctor and the patient have mutual respect, are not competitive, and both are capable of listening with attention and interest. If a doctor does not seem interested, finding another doctor would be wise. If the doctor admits unfamiliarity with post-polio syndrome and is not interested in learning more, then that doctor should refer you to a colleague who is both more knowledgeable and more interested.

The best outcome is to find a doctor who knows about post-polio syndrome or is willing to learn, is a good listener, is not obviously hurried, respects all of his/her patients, and takes a genuine interest in you as a patient with a problem and as a person. You will know when you have found a doctor with whom you can relate. ☞

Our Appreciation

The following individuals were recognized as significant people, past and present, to the lives of those who donated.

To The Gini Laurie Endowment in honor of ...

Linda Bieniek

Meredith Thomas

Mrs. Donald (Pat) Miller

To The Gini Laurie Endowment in memory of ...

Louise Conrad

Effie Otto

Richard Estill

Pauline Schaibel

Daniel Ezydorski

Fred and Elaine Schmick

June Helen Fortezzo

Evelyn G. Wagoner

Clayton Mallory

Don Willfong

Douglas A. Martin, PhD

Edward Andrew (Andy) Young

To The Research Fund in memory of ...

Andrew Chudy

Effie Otto

To The Gini Laurie Endowment from Support Groups ...

Polio Survivors of Oklahoma Associates, Inc.,

Oklahoma City, Oklahoma

In memory of Richard Estill

Polio Survivors Plus, Lake Forest, California



(left to right) Jose Isola, Virginia Walls, PT, María Fasabi, Lauro S. Halstead, MD, Frederick M. Maynard, MD, and Marilu Montero.

Training in Columbia and Jamaica

Armand E. Zilioli, MD, orthopedic surgeon and polio survivor, of the VA Hospital in Saint Petersburg, Florida, was a visiting lecturer on post-polio in Barranquilla, Columbia, last year. He lectured in Spanish to over 75 medical school professors, physical and occupational therapists, as well as clinicians. He made rounds of the OT and PT facilities at their children's hospital and reviewed a number of clinical facilities.

He also was the guest lecturer at the Sir Robert Golding Rehabilitation facility in Kingston, Jamaica, where he examined polio patients.

CALENDAR 2003

September 19

AGING WITH A DISABILITY: THE LATE EFFECTS OF POLIO.

Oakland Marriott/Convention Center, Oakland, California.

Sponsored by The Kaiser Permanente National CME Program. Hosted by Kaiser Permanente Foundation Rehabilitation Center, Vallejo, CA in cooperation with a coalition including the San Francisco Bay Area Polio Survivors (SFBAPS). Contact Phyllis Hartke (925-934-6103, sfbaps@aol.com).

September 20

OHIO POLIO NETWORK'S CONFERENCE.

Holiday Inn-Cleveland West, Westlake, Ohio.

Contact Alice Sporar (440-461-7133, amsporar@worldnetoh.com).

Training in Peru

Marilu Montero and Jose Isola, founders of the Sociedad Peruana de Polio (Peruvian Polio Society), invited Lauro S. Halstead, MD, and Virginia S. Walls, PT, National Rehabilitation Hospital, Washington, DC, and Frederick M. Maynard, MD, Marquette, Michigan, to organize training about the late effects of polio for health care professionals in Lima. They examined 30 post-polio people who were selected for their interesting and broad array of typical, challenging, complex medical and rehabilitative problems.

The team from the States examined the polio survivors with the Peruvian health professionals observing on the first two days. The twelve Peruvian doctors and seven therapists examined patients on the last two days, with the team watching, critiquing, and discussing management strategies. Several of the professionals and their administrative leaders plan to organize a post-polio clinic, where doctors and therapists will expand their experience and knowledge about post-polio problems.

The Sociedad Peruana de Polio also received some support from their District Rotarians to buy wheelchairs, crutches, and other equipment that people need but cannot afford to buy.

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HOW TO CONTACT US ...



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